Children with diabetes: Protecting our future
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International Diabetes Federation

Promoting diabetes care, prevention and a cure worldwide

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NO MORE EXCUSES

It always seems impossible, until it is done. – Nelson Mandela

These words first uttered by Nelson Mandela seem particularly appropriate and current for what is most critical to the status of diabetes care in the world today, especially concerning human rights and survival. Mandela’s words reflect the pressure most nations, governments and municipalities must accept in order to improve the current state of care for all people living with type 1 or type 2 diabetes worldwide – especially children. With cautious optimism, and with the largest coalition of diabetes advocates behind us we must be ready to fight for and protect the fundamental rights of each and every child living with diabetes. It may seem impossible today, but it must get done.

There was a time when it seemed impossible to save the lives of children suffering from diabetes, that is until Drs. Frederick Banting and Charles Best, mentored by Professor Macleod and assisted by James Collip, discovered insulin in 1921. The first child successfully treated with insulin took place in 1922 at Toronto General Hospital. Dr. Banting injected 14-year-old Leonard Thompson, a ‘charity patient,’ with the hormone insulin and Leonard survived, as so many children have done ever since. However, it also must be pointed out that even today many children do not thrive, and many die within weeks of diagnosis, if they are even diagnosed at all.

We must ask ourselves again and again how can it be that we live in a world where type 1 diabetes is still considered a death sentence, even though a life-saving treatment was discovered nearly a century ago?

In 2006, landmark UN Resolution 61/225 was the first step toward advancing the rights of people affected by type 1 and type 2 diabetes. Resolution 61 validated the debilitating and costly nature of diabetes.

Tragically, within one year of Resolution 61, nearly 5000 children still died from diabetes mellitus worldwide (WHO Global Burden of Death, 2008). Even this shameful statistic is a probable inaccuracy due to under-reporting, misdiagnosis and guilt. What is not alluded to in Resolution 61 is the multitude of children, from low- and middle-income countries, who develop diabetes and find themselves very much alone. Many of these children suffering with poorly treated diabetes are too afraid to reveal their condition to teachers or schoolmates and many won’t be afforded the same opportunities for career or life. The undiagnosed and neglected child who develops diabetes will not be satisfactorily cared for and now we know that care in the beginning is key to diminishing the risk for complications later in life. Most tragically of all, the child who develops type 1 diabetes, but who also lives in poverty, will die within 2 weeks without insulin.

It is time that we ensure that medical standards for all children suffering with type 1 diabetes are met. It is time the provision of insulin is made accessible to all who might need it – but especially children.

No more excuses.

Today, under the leadership of Graham Ogle, IDF’s Life for a Child (LFAC) Programme helps 11,200 children and youth in 43 countries and provides them with essential care including insulin, test strips, and expert diabetes education. However, it is estimated that 80-100,000 children and youth around the world are still in urgent need of assistance.

In 2011, IDF developed the first ever International Charter of Rights and Responsibilities of People with Diabetes providing fundamental guidelines for the rights of more than 371 million people living with diabetes. This landmark document places the rights of people with diabetes, their parents and carers into three focus areas: the rights to care; information and education and social justice, whilst at the same time acknowledging the responsibilities held by people with diabetes.

The Charter aims to bridge the gap in the quality of care as well as customs and practice that impact the health of people with diabetes in many ways. But there is so much more we need to get done for the promise of a healthy future for the child living with diabetes.

Children must have a voice. In order to have an understanding of their health requirements, our youth must be able to communicate their needs and explain what aspect of diabetes is troubling them most so they can begin to live healthy lives with the promise of a future. For this reason psychosocial counselling and care is key for the child who is not meeting targets. This aspect may be especially apparent in adolescence and young adult life well into the mid-twenties. Communication between doctor and patient, counsellor and patient and parent or carer brings to mind the triangle of care. As a child develops into a young adult it is important that the right transitional care is chosen. We know that young adults and adolescent children are more susceptible to complications. We cannot overlook the importance of teaching children living with diabetes to fight their condition and overcome perceived barriers. We must teach them to be masters of the disease rather than its servant, but only with adequate care and access to life-saving medicines can we begin to show them the way.

No child should die of diabetes, and we must ensure this gets done.

Michael Hirst
President, International Diabetes Federation
Both studies are from the USA. The question of feasibility must be much more marked in low-resource environments.

Another recent Diabetes Voice article (Lind, et al, available on-line) is the demonstration that, at least in Canada and the UK, prospects seem to be improving in terms of mortality outcomes for people with diabetes compared with people without diabetes of the same age. Overall, the excess mortality of people with diabetes has fallen from about twice that of people without diabetes in 1996 to around one-and-a-half times in 2009. This is still not satisfactory but it is a trend in the right direction. The authors speculate that this fall is ‘in part due to earlier detection and higher prevalence of early diabetes, as well as to improvements in diabetes care’. It’s too early to unfurl the flags and sound the trumpets yet since we need data like these from other countries but it is encouraging to feel that the prospects for our children may be better in the future than they were in the past.

On the last page of this issue is a new feature – Voice Box – the Diabetes Voice Inbox. Your comments on our publication are invited – via diabetesvoice@idf.org. Please keep them coming in. We are aiming for this magazine to be interactive as well as active.

Oft-repeated statements about our children, though they have become clichés, are nevertheless absolutely true. Our children are our future. They are our most precious resource. Their welfare is one of the few things that everyone in the world would agree is worth striving for. Politics, religions and customs still, unfortunately and sometimes tragically, divide us but the welfare of our children is one of the concerns that unites us – without any question whatsoever. The theme of this issue of Diabetes Voice is diabetes in children and adolescents. Unless we focus on this theme - and act - the welfare of our children and adolescents who have diabetes – either type 1 or type 2 – will suffer. If we let that happen, how will we explain our failing to them now and when they are adults?

I was pleased to see, in a recent issue of Diabetologia, the paper by Persson and colleagues dealing with the impact of childhood-onset type 1 diabetes on schooling – educational achievement at the end of compulsory education and the end of upper secondary education – and on employment status later in life. As someone who has, from time to time, contributed to the literature on the individual and societal costs of diabetes, I have often thought that the ‘cost’ (in the widest sense) of diabetes on the education of children was virtually unrecorded. In contrast, the monetary cost of diabetes to the individual and family and the cost to society of lost production of adults with diabetes have both been intensely studied. That study, from Sweden, found that the presence of diabetes had an adverse effect on children’s final grades and that those who had diabetes as children were less likely to be ‘gainfully employed’ at the age of 29. As was highlighted in a commentary on the paper in the same issue of the journal, the effects found were small in magnitude but their magnitude is likely to be very dependent on the nature of the support given to children in any particular school system. Thus, though small in Sweden, the effects may be much larger elsewhere. My hunch would be that they are.

The first of the selection of articles in the ’Currently in Diabetes Research and Clinical Practice‘ section of News in Brief in this issue is specifically about children. It’s a study which asks the question: do attitudes to blood glucose monitoring of children with type 1 diabetes have an impact on family harmony? The short answer is: yes, they do. Further on in this issue is an article, originally published in the same journal, about a different aspect of the same topic: to what extent are the recommendations of children’s care providers (i.e. diabetologists and diabetes specialist nurses in the main) about the frequency of self monitoring of blood glucose actually carried out in practice?

Authoritative guidelines on the monitoring of blood glucose in type 1 diabetes are demanding – four or more tests per day in most instances. This has a cost – financial (either to the health system or to the family, depending on circumstances), practical (in terms of the time and facilities needed to carry them out) and emotional (in terms, for example, of the constant reinforcing of being ’different’ from everyone else who don’t need to do this). Both studies have approached, from different perspectives, the multi-faceted question of the feasibility of adhering to these guidelines.

Rhys Williams is Emeritus Professor of Clinical Epidemiology at Swansea University, UK, and Editor-in-Chief of Diabetes Voice.
World Diabetes Day 2013 campaign: protecting our future one step at a time

'Take a Step for Diabetes,' the World Diabetes Day 2013 campaign, encourages people worldwide to participate directly in the drive for improved diabetes awareness by stepping up or accounting for any physical or diabetes related activity.

The 'Take a Step for Diabetes' online platform is rapidly accumulating millions of step donations collected through various individual and group activities. One step equates to any activity that advances awareness, improves the lives of people with diabetes, promotes a healthy lifestyle or reduces the risk of developing diabetes. In recognition of the current number of people living with diabetes, 'Take a Step for Diabetes' hopes to achieve 371 million steps by the start of the IDF World Diabetes Congress in Melbourne, December 2013. Over 200 million steps have been submitted so far.

Find out how you can take part at http://steps.worlddiabetesday.org. Every step forward is a step toward advancing diabetes care, prevention and a cure worldwide. Help us change diabetes one step at a time!

The World Diabetes Day campaign also features a public service announcement (PSA) produced to inform and educate people about the life-threatening nature of diabetes. The 60-second PSA, produced by the IDF, promotes the importance of staying healthy to help reduce complications associated with diabetes, such as amputation, blindness and heart disease.

The PSA can be viewed at http://bit.ly/1bKJauI

How much do you know about diabetes? Are you interested in helping raise awareness or becoming a diabetes advocate in your area? All this information and more is available in the World Diabetes Day online toolkit, displayed in a user-friendly format and tailored to different target groups including the general public, people with diabetes, children and youth, and health professionals.

The toolkit is available at www.idf.org/worlddiabetesday
In early June, over 100 children and young people with type 1 diabetes and their families gathered at the Palace of Westminster in London, UK, for the parliamentary launch of Diabetes UK’s ‘Type 1 essentials for children and young people’ campaign. Diabetes UK estimates that only 6% of children and young people in the UK are getting all (‘ten out of ten’) of the recommended diabetes care, services and support that they are entitled to. These are:

- Care from a specialist team
- Regular checks (HbA1c, weight, height etc.)
- The right treatments
- Support for self- or parental-care
- Help with feelings or worries
- The right care in hospital
- A smooth transition to adult services
- A say in the care they get
- Support at school
- Equal opportunities

were supported by the project to attend foot screening and care training at the University of Johannesburg in the middle of July. There they participated in lectures and workshops developed by the South African university and Egypt’s Université Senghor designed to lead to certification as Diabetes Foot Care Assistants.

When they return to their centres in Cameroon, Ghana, Guinea, Kenya, Madagascar, Republic of Congo, Rwanda, Senegal, Tanzania and Uganda, the trained health care professionals will use a specially developed risk stratification and intervention tool to tackle the high rate of foot complications in the countries.

The campaign serves to make children’s diabetes teams aware of the support that children and young people with type 1 diabetes should be receiving and encourages the lobbying, by young people and their parents, of their members of parliament (MPs) and local health care managers to ensure that these features are in place in their localities. Children and their parents met with their MPs on the day while a few families also met with the Minister responsible for diabetes, Anna Soubry.

More information at: www.diabetes.org.uk

DAFI – the innovative multistakeholder Diabetes Foot Initiative in Africa – has taken a great stride forward in recent weeks.

The project led by IDF and its Africa Region, in collaboration with the University of Johannesburg, Université Senghor, UNFM, Sanofi Diabetes and ten healthcare centers in Africa, is now well underway. Specialist training of health care professionals is on course to help people with diabetes in ten African countries avoid the trauma of diabetic foot and the risk of lower limb amputation.

After an initial internal e-diabetes training with UNFM, thirty physicians and nurses were supported by the project to attend foot screening and care training at the University of Johannesburg in the middle of July. There they participated in lectures and workshops developed by the South African university and Egypt’s Université Senghor designed to lead to certification as Diabetes Foot Care Assistants.

At the same time a suite of materials has been developed to raise awareness among people with diabetes living in the ten selected countries about the need to care for their feet to prevent complications or existing foot problems worsening.
**CURRENTLY, in Diabetes Research and Clinical Practice**

**DRCP** is the official journal of IDF. The following articles have appeared recently or are about to appear in that journal. Access information can be found in the QR code.

**IMPACT OF BLOOD GLUCOSE MONITORING AFFECT ON FAMILY CONFLICT AND GLYCEMIC CONTROL IN ADOLESCENTS WITH TYPE 1 DIABETES**

‘This longitudinal study examined whether diabetes-specific family conflict and glycemic control were impacted/explained by negative affective responses to blood glucose checks.’

**GLOBAL DIABETES SURVEY – AN ANNUAL REPORT ON QUALITY OF DIABETES CARE**

‘The Global Diabetes Survey … is a standardised, annual, global questionnaire that will be used to assess responses of representatives from 19 diabetes-related stakeholder groups … The findings will be freely available for everyone’s use and will be used to inform politicians and stakeholders to encourage the improvement of the quality of diabetes care in its medical, economical, structural and political dimensions.’

**ARE RECOMMENDED STANDARDS FOR DIABETES CARE MET IN CENTRAL AND SOUTH AMERICA? A SYSTEMATIC REVIEW**

‘We evaluated quality of diabetes care in low- and middle-income countries (LMIC) of Central and South America … We also identified barriers to achieving goals of treatment and characteristics of successful programs. … Few studies report quality of diabetes care in LMICs of the Americas, and heterogeneity across studies limits our understanding. Greater regard for audits, use of standardized reporting methods, and an emphasis on overcoming barriers to care are required.’

**ON THE BOOKSHELF**

**DIABETES ABC**
By Dr. Sherry L Meinberg
Illustrated, 56 pages, Outskirts Press (November 7, 2012)

*Diabetes ABC* is a simple overview of diabetes and related conditions written for both children and adults, providing tips for parents, caregivers, friends, children and teachers about living with the illness.

**DIABETES AND ME: AN ESSENTIAL GUIDE FOR KIDS AND PARENTS**
By Kim Chaloner (Author), Nick Bertozzi (Illustrator)
Illustrated, 176 pages, Hill and Wang (November 5, 2013)

Author Kim Chaloner was diagnosed with type 1 diabetes at age sixteen. Drawing on her own experiences, Kim walks the reader through the basics of type 1 and type 2 diabetes covering the latest technologies for monitoring blood sugar, strategies for nutrition and exercise, how to explain diabetes to friends and family members and more.

**PUTTING YOUR PATIENTS ON THE PUMP**
By Karen M. Bolderman (Author), Nicholas B. Argento (Contributor), Susan L. Barlow (Contributor), Gary Scheiner (Contributor)

*Putting Your Patients On The Pump* provides practical instructions for integrating all the essential elements of a safe and successful insulin pump programme including: patient selection and education, starting doses and fine-tuning, and long-term maintenance. Unique issues surrounding special populations such as children and pregnancy are covered in detail. An essential resource for the healthcare professional who requires a desk reference or instructional guide.

www.idf.org/diabetesvoice
Aminath Abdul Rahman (Aana) was born in 1985 in Malé, the capital of the Republic of the Maldives Islands situated just southwest of Sri Lanka in the Indian Ocean. Her country’s national tourism campaign – ‘the sunny side of life’ – reflects the island nation’s international reputation as the ultimate tropical luxury for newlyweds in search of paradise. Consisting of 1190 islands of which only 200 are inhabited, the Maldives was designated as a ‘least developed country’ (LDC) by the United Nations until 2011 when it graduated to upper middle-income status. Prevalence of diabetes in the Maldives (pop. 316,000) is 9.8% and the total number of people living with undiagnosed diabetes hovers just above 8%.1

Today, the greatest challenge faced by people with diabetes in the Maldives is the lack of access to medically necessary diabetes medications or supplies. Multiple injections based on basal-bolus therapy are impossible to administer because even today the only available insulin is long acting insulin. To make matters worse, insulin is only available in the capital because delivery to other outlying islands in the Maldives is too difficult. Learn about one young woman’s journey with type 1 diabetes in the Maldives as told by Aana Rahman with the help of Aishath Shiruhana, CEO of Diabetes Society of Maldives.
I was diagnosed with diabetes at the age of nine in 1994. Back then most people living in Malé, including healthcare professionals, were not aware of type 2 diabetes, let alone type 1 diabetes. Unfortunately, no one told my family much about my condition when I was first diagnosed. My mom and dad did not receive any information about the basics of diabetes from the doctors and the only tertiary care hospital in Maldives did not have the necessary tests to determine whether I had developed type 1 diabetes or type 2 diabetes. Instead, I was put on type 2 oral medication based on my hyperglycaemic or high blood glucose symptoms and the wrong medication ultimately led to diabetic ketoacidosis (DKA). Due to my constant fluctuating blood glucose levels and after one too many hospitalizations, I was finally put on insulin therapy and told I had type 1 diabetes. Unfortunately, the doctors had no choice but to give me the only commercially available insulin in Malé, Human Mixtard 30/70, dispensed at the government pharmacy. This was the only insulin available if you lived with diabetes in the Maldives at the time.

It took more than ten years, but things were going to get better for me. My first experience learning about diabetes was in 2005 when I joined the Diabetes Society of Maldives (DSM). It was very exciting and worthwhile for me because I was given free medical supplies, such as blood glucose testing kits, right after I registered. I immediately got involved in DSM activities as a volunteer and the Society became my second family and my virtual cheerleading team on the diabetes battlefield. Since I joined DSM, I have never stopped learning. I know that there are many children like me who are grateful for diabetes assistance from the Society. In 2008, DSM established a programme for children living with diabetes in the Maldives (DSM). It was very exciting and worthwhile for me because I was given free medical supplies, such as blood glucose testing kits, right after I registered. I immediately got involved

Since I joined DSM, I have never stopped learning. I know that there are many children like me who are grateful for diabetes assistance.

Diabetes Society of Maldives (DSM) was established in April 2000 and became a member of IDF in 2002 to establish greater awareness in the Maldives about diabetes, help patients lead a full and healthy life with diabetes and emphasize the importance of diabetes prevention.

DSM, with a current membership of approximately 1200 people, is the centre for information on diabetes in the Maldives and we educate the community through free consultations, screening programmes, and presentations all related to health education. This year, we had well over 100 new members join the society and generally had about 1250 follow-up appointments at the clinic. In addition, DSM is continually working to generate awareness and improve diabetes care throughout the Region. The result of this effort is best reflected in the 2012 diabetes screening and awareness programmes which found that 50% of nearly 4000 participants screened were at high risk for developing type 2 diabetes.
type 1 diabetes called ‘Save a Diabetic Child’. Funded by the International Diabetes Federation’s Life for a Child (LFAC) Programme and other local donors, ‘Save a Diabetic Child’ ensures that all registered children living with type 1 diabetes in the Maldives are provided with insulin and testing kits.

Campers at the first diabetes youth camp in the Region understood the important relationship between diabetes self-management and the promise of a successful future.

My relationship with DSM continued to thrive for a few years, but my connection to the International Diabetes Federation (IDF) began when I was given the opportunity to attend the first Young Leaders in Diabetes (YLD) Programme held concurrently with the World Diabetes Congress in Dubai 2011. I was the only member representing the South East Asian (SEA) Region and because of this, I was selected to be the SEA representative for the YLD Council. One of my first assigned projects was to conduct a five-day diabetes youth camp for 18 children living with diabetes from across the Maldives. As the first diabetes youth camp in SEA, the main goal of the programme was to foster diabetes acceptance and help participants feel at ease in a community where having diabetes is the rule, not the exception. The campers went home feeling more self-confident, and self-reliant having understood the important relationship between diabetes self-management and the promise of a successful future. I hope to facilitate more diabetes camps in the future with the support of DSM and YLD. As a yearly programme, and with the help of DSM, I also established a youth group for diabetes called ‘My Sweet Family’ which acts as an outreach programme all over the Maldives.

For so long I thought having an insulin pump was an impossible dream.

This year, I have been selected as an organizing committee member for YLD Leadership Training at the World Diabetes Congress in Melbourne 2013. It is also an amazing year for a different reason. For so long I thought having an insulin pump was an impossible dream until this May when a donor selected me as the recipient of my very own pump. I am happy to report that I have finally been able to achieve my glycaemic targets with my new pump!

I am going to work hard with DSM to make every effort possible to provide insulin pumps to all children in the Maldives. There is nothing more important than making the dreams of children with diabetes a reality.

References
Protecting kids' rights: IDF and select partners launch Kids and Diabetes in Schools (KIDS) project in Brazil and India

Anne Belton and Bénédicte Pansier

Diabetes is increasingly becoming a more common health threat for young people across the world, demanding local communities – particularly those in low- and middle-income countries – execute measures that will ensure young people with diabetes can live equally rich and fulfilling lives as their peers. In collaboration with select partners, the International Diabetes Federation has developed a project designed to support children’s rights, ensuring school days are happy days for the diagnosed, and encouraging healthy behaviours among all school-aged children worldwide.

In June 2013, IDF, in collaboration with the International Society for Paediatric and Adolescent Diabetes (ISPAD) and Sanofi Diabetes, launched the Kids and Diabetes in Schools (KIDS) project. KIDS, as a multi-stakeholder initiative, aims to foster a safe and supportive school environment for children with diabetes to manage their diabetes and fight discrimination. The fundamental rights of children living with diabetes include the freedom to access care and support to manage diabetes appropriately and to be fully included and engaged in all school activities to achieve their full potential. KIDS also aims to raise awareness of diabetes and promote healthy diet and exercise habits in the school community.
Implementing and integrating KIDS into school communities successfully requires serious commitment from policy makers and education authorities; completion of situational analyses summarizing opportunities and challenges; execution of a fully-fledged school awareness campaign; and development and introduction of a diabetes school information pack and teacher training for selected countries. IDF’s Young Leaders in Diabetes Programme will lend support and help disseminate the KIDS packs when the project kick-starts in Brazil and India, our two pilot countries.

At the end of the first phase of the project (18 months), a Global Diabetes in Schools Toolkit will be developed and made available to IDF Member Associations to roll out the project, after the pilot launch, in other successive parts of the world. In the second phase, KIDS aims to achieve government support for systemic change for children with diabetes in schools including dissemination of national guidelines.

Global threat of childhood diabetes
Type 1 diabetes is one of the most common chronic childhood diseases, affecting an estimated 490,000 children under 15 years. The incidence of type 1 diabetes among children is increasing in many countries and approximately 78,000 children under 15 years are estimated to develop type 1 diabetes annually worldwide.1-3

Type 2 diabetes in childhood has the potential to become a global public health issue.

Young people today also face another danger that threatens their ability to attain a healthy and successful future. Evidence shows that type 2 diabetes is also increasing in children and adolescents around the world at alarming rates. With rising levels of childhood obesity and physical inactivity in many countries, type 2 diabetes in childhood has the potential to become a global public health issue.4-6

Against this backdrop, the school system is a vitally important environment for children with diabetes, especially as it relates to day-to-day self-management care and total well-being. Schools perform a critical role supporting and educating children with diabetes so they have the same opportunities afforded other children, such as participating in the classroom or playground.

IDF leadership for childhood diabetes
In March 2005, IDF released a position statement on the Rights of the Child in the School declaring that children have the right to manage their diabetes without being excluded or discriminated against in the school setting. The Position Statement calls for all children with diabetes to have an individualized diabetes plan devel-
oped in a collaborative approach with healthcare providers, school staff and the family.

Numerous guidelines and educational materials on diabetes in schools for teachers, parents and children have been made available in several countries. Effective campaigns about diabetes management in schools include the Australian Diabetes Council’s ‘Diabetes kids and teens careline’ (2006), the American Diabetes Association’s ‘Safe at School’ Campaign (2011), Diabetes UK Children’s Campaign ‘Let’s Talk Type 1 Diabetes in Schools’ (2011), the IDF and its Italian Member Association’s ‘Good Diabetes Control’ campaign for schools (2012/2013) and the Diabetes Program at Schools in Turkey (2012).

Despite this work, evidence suggests that many children and adolescents with diabetes continue to face barriers to education and endure discrimination and stigma, in particular in low- and middle-income countries. School and national policies don’t often recognize the special needs of a child living with diabetes. Lack of the assistance needed to monitor blood glucose, administer insulin and treat emergency situations (e.g. hypoglycaemia) can result in the child being excluded from school activities. Some schools believe they reserve the right to deny access to a child with diabetes and even when allowed to matriculate, some children are barred from participating in extracurricular activities. Ignorance and misconceptions about diabetes held and fostered by school personnel, fellow students and parents of other students are often at the root of such stigma and discrimination. Furthermore, a school classroom may not provide clean and adequate space to support self-management tasks such as testing blood glucose, storing snacks, injecting insulin or storing equipment for injections or lancets for blood glucose testing.

Endpoints of KIDS - Phase 1

The IDF KIDS project will begin with a feasibility study supported by two local implementing partners, the IDF Member Association Associação de Diabetes Juvenil (ADJ) in Brazil and the Public Health Foundation of India (PHFI). This feasibility study will identify and engage with relevant stakeholders at national, regional and local levels, review existing guidelines and initiatives on diabetes in the school environment and carry out a needs assessment in the two countries. The results are expected by September 2013.

References

A look 'upstream' to Melbourne

In the spirit of patient centeredness

Angus Forbes

Are the latest treatment innovations enough for people living with diabetes in the 21st century? How can the medical profession utilise current technologies and treatment innovations without losing touch with patient values and the power of compassion and insight?

Leading the way for the Education and Integrated Care Stream, Angus Forbes allows us to ‘shadow’ the exciting programme planned for Melbourne 2013. Care integration and patient-centeredness will be threaded throughout lectures, discussions and symposia with renewed energy and insight. To reflect the importance of empowerment, people living with diabetes will be actively participating in forums and discussions alongside healthcare providers. Switching to a broader perspective, global variations in innovation, education and self-management care will be reviewed, helping to address the need for a worldwide diabetes care reality check.

The Education and Integrated Care Stream scheduled for the IDF World Diabetes Congress in Melbourne will address global perspectives on key dilemmas associated with diabetes self-management innovations in the 21st century. Today’s advances in diabetes medical therapies continue to expand opportunities for improving treatment and management strategies. However, advanced treatments are only effective if people with diabetes can use them appropriately and accommodate them within their daily lives. There is also growing recognition within the diabetes community that an individualised approach to diabetes care may lead to enhanced adherence to therapy. Individualised programmes should identify more than just individual risk assessment, and actively involve people with diabetes in identifying their own targets and treatment decisions.

Consequently the value of diabetes innovations, especially those designed to motivate people and reinforce positive self-management behaviours, is directly linked to improved outcomes making them essential for advancing diabetes care.
Care integration has been a key buzzword in the healthcare landscape for the last decade. Currently identified as one of the most important qualities for the development of effective care systems in diabetes, integration is a professional healthcare preoccupation because the collective approach of providing patient-centred care, quality, safety and efficiency all in one is demanding. Care integration is an overarching theme embedded throughout the Stream, and we will examine important areas where integration is challenging, especially for mental health and diabetes; transitions across the ages and in the context of gender; integrating alternative health models; the interface between the person with diabetes and family members; and innovative approaches to integrating care systems.

**Advanced treatments are only effective if people with diabetes can use them appropriately and accommodate them within their daily lives.**

Is person centeredness, regarded as a central tenant of modern diabetes care, a reality for people living with diabetes? To answer this question, we will be sharing key multinational data that may reveal whether patient values actually guide clinical decisions. In the spirit of patient centeredness, we will facilitate discussions and ask people living with diabetes about current trends in patient education. We will also examine alternative techniques for engaging patients in their care, including the use of narrative medicine and through media such as art and storytelling. We are privileged that one of the leading advocates of a patient centred approach to diabetes education, Professor Jean-Philippe Assal, will...
present a lecture entitled, ‘Power and fragility in health, illness and disease: the role of healthcare providers and patients’ as part of the Melbourne programme.

Is person centeredness, regarded as a central tenant of modern diabetes care, a reality for people living with diabetes?

Additionally, we will consider the important area of adherence, which we know is a significant predictor of diabetes complications.4 Many factors contribute to adherence, and the programme will highlight some current innovations in this area including sessions on the potential of asking more from patients in the development of therapies; quality use of medicines; and how innovations actually enhance adherence. E-health technologies are evolving rapidly in tandem with the changing way people communicate and interact more generally. In addition to the use of social media and mobile health (m-health) interventions, we will discuss how new technologies can be integrated within the wider care system and how the potential for greater self-management support is enhanced.

There will be a symposium on the challenging area of type 2 diabetes prevention in young people. Clearly with rising childhood obesity levels there is an urgent need to develop effective strategies to help young people become more active and consume less highly refined carbohydrate.5 We will be exploring this from a number of perspectives, including innovative work on the use of play to increase activity and through integrated programmes targeting schools, families and the environment.

Finally, reflecting the global nature of the Congress, we will have presentations from different regions, highlighting innovative strategies from all over the world. Presentations from low- and middle-income countries (LMICs) will examine how innovative education programmes are often executed with limited resources. We will also explore global variations in access to psychological and self-management care with a special symposium from the DAWN 2 Study.6 The programme will showcase current trends in diabetes education worldwide. There will also be special sessions on controversial topics such as current dietary trends (weeding out the fads) and scrutiny related to extreme levels of exercise. Opportunities for participants to interact with these important topics through interactive discussions and in workshops will be provided.

Angus Forbes
Angus Forbes is FEND Professor of Clinical Diabetes Nursing at King’s College London, UK. He leads the Education and Integrated Care Stream at the IDF World Diabetes Congress in Melbourne, 2013.

References


A look 'upstream' to Melbourne

Prioritising diabetes on the global agenda

Linong Ji

The global impact of diabetes in the 21st century has been compared to the after-effects of a tsunami: diabetes threatens the future of many millions and crushes the stability of national health and economic systems. Climate change, globalisation, urbanisation, changing demographics and economic shifts are all part of the bigger global picture in which diabetes plays an increasingly dominant role.

Professor Linong Ji, lead for the Global Challenges in Health Stream, introduces the upcoming Melbourne programme, explaining the obligation of all sectors to prioritise diabetes. Invited experts will examine what we must do to frame diabetes within the larger public health context and secure a healthier future for everyone, irrespective of their geographic location.

The Stream will provide a comprehensive look at the global challenges facing diabetes care and treatment today and ask the big questions relating to diabetes and global health. How can we create national diabetes plans which will be helpful not only to people with diabetes but also to people at risk? What should the role of WHO and other international organisations be in creating these plans? What is the impact of globalisation and urbanisation on diabetes and how can we mitigate their negative effects? Speakers from all over the world will identify what works both locally and globally in terms of combatting the epidemic and what still needs to be done. Our objective should be to foster real change for people with diabetes and those at risk.
Advocating change
IDF in cooperation with the NCD Alliance has been at the forefront of global health advocacy, working to position diabetes and other Non-communicable Diseases (NCDs) on the global health agenda and the post-2015 development agenda. In 2012, the World Health Assembly took a crucial step in acknowledging the problem by setting a target to reduce preventable NCD deaths 25% by 2025. Experts in the Global Challenges in Health Stream will consider this target alongside the historic target to ‘halt the rise in diabetes,’ with a constructively critical eye. Are the WHO targets hype or hope? How do we achieve them in low-and middle-income countries?

An ageing society and its accompanying challenges to public health will be another essential focus of the Stream. In 2030, the number of people over 60 will outnumber those under fifteen for the first time. As the age of populations increase, so does the overall risk for developing type 2 diabetes. The increasing number of co-morbidities in an ageing population also complicates treating diabetes in this population. Stream sessions dedicated to ageing will focus on our health systems and whether or not they are ready to deal with the impact of rapidly changing demographics.

From global to local
Unless we can make an impact on the lives of people with diabetes in the ‘real world,’ discussion and debate on research outcomes will fall short of making a real difference. The Global Challenges in Health Stream will therefore focus a large part of its attention on how we can translate research to real world settings. Unified, we can fight the epidemic on the diabetes battlefield, where the disease continues to claim so many lives in communities and societies.

We hope you will join us for our sessions because this really is about you! I look forward to seeing you in Melbourne and joining together to shape the future of diabetes.

Linong Ji
Linong Ji leads the Global Challenges in Health Stream at the IDF World Diabetes Congress in Melbourne, 2013. He is a Professor of Medicine, Director of the Department of Endocrinology and Metabolism at Peking University People's Hospital and Co-Director of Diabetes Centre of Peking University. He is the recent President of the Chinese Diabetes Society and a Vice-President of the International Diabetes Federation.
In 2010, Turkey’s Diabetes Program at School was developed as a joint protocol initiated by the Turkish Society of Paediatric Endocrinology and Diabetes in cooperation with the Ministry of Education and Ministry of Health. Objectives of the programme targeted school communities across Turkey in order to raise awareness about type 1 diabetes, provide better diabetes paediatric care, improve nutritional standards for school children and prevent obesity. In just two years, a number of trained teachers detected symptoms of diabetes in 40 undiagnosed children. Şükrü Hatun and Şeyda Özcan explain why and how they achieved so much in so little time.

All school children with diabetes deserve the same educational opportunities as their healthy peers. Teachers and school staff have the responsibility to create an equal opportunity learning environment for all children, including those with diabetes. Educating teachers about diabetes and organizing the school environment for better diabetes care will reduce the problems faced by children with diabetes in school and improve their quality of life. Providing diabetes awareness in the school environment may also assist with early detection and diagnosis.

Children and diabetes in Turkish schools: eliminating the avoidance of care
There are approximately 20,000 children, mostly of school age, living with diabetes (mostly type 1) in Turkey. Unfortunately, many children living with type 1 diabetes and their families encounter problems in accessing the school environment and participating in school programmes. According to a recent study, upon returning to school, the HbA1c of children with type 1 diabetes increased and they had problems with their diabetes care. Some children with type 1 diabetes are forbidden to participate in physical education and some activities such as school trips are off limits. It has been reported that some infant nurseries and kindergartens refuse registering children diagnosed with diabetes to avoid the responsibility of care. Children with type 1 diabetes are sometimes labelled as sick and are viewed as abnormal due to little awareness or facts about diabetes. On the contrary, children with diabetes should not only be allowed access, but also motivated to participate in all activities with their schoolmates. To accommodate students with diabetes, a school nurse or a counsellor should be trained on basic diabetes care. Other diabetes care requirements may include a private space for measuring blood glucose and injecting insulin as well as the provision of healthy school meals, refreshments and toilet breaks during...
classes. Moreover, teachers should learn the signs of diabetes and be able to recognize symptomatic children earlier in order to avoid serious events such as diabetic ketoacidosis.

One third of children have also developed an increased risk for adulthood obesity and/or type 2 diabetes.

The diabetes care and detection concern in schools becomes even more complex with the growing problem of weight-gain and obesity in childhood. Obesity frequency among the age group of six to sixteen years has increased from 5% to 10.5% (16.3% among high income level group) in the last eight years in Turkey. One third of children have also developed an increased risk for adulthood obesity and/or type 2 diabetes. Childhood obesity is caused primarily by poor lifestyle habits including the consumption of high-calorie or processed junk food such as sugar-sweetened beverages, and physical inactivity. Preventing obesity in adulthood depends mainly on the efforts in childhood and around puberty. In recent years, the government has directed more attention to childhood nutrition, and the Radio and Television Supreme Council (RTÜK) has limited advertisements that promote high-calorie food. Turkey’s Ministry of Education has also restricted sales of junk food and sugar-sweetened beverages at schools.

Aim of Diabetes Program at School

The Diabetes Program at School was developed as a joint protocol initiated by the Diabetes Working Group embodied in the Turkish Society of Paediatric Endocrinology and Diabetes in cooperation with the Ministry of Education and Ministry of Health. Target groups of the Diabetes Program at School include all professional teachers across Turkey, teachers who currently oversee the education of children with diabetes, members of the paediatric diabetes medical team, local representatives of the Ministry of Education and Ministry of Health and school administrators.

The objectives of the programme are to:

- Raise school community and teacher awareness about type 1 diabetes
- Ensure early diagnosis of type 1 diabetes and decrease the frequency of diabetic ketoacidosis among school children.
- Provide better care for children with diabetes
- Create a healthy nutrition attitude among school children
- Raise awareness about obesity

Diabetes Program at School materials and activities

The Diabetes Program at School, officially initiated on November 12th, 2010 in Istanbul, succeeded in drawing together a large group of teachers and securing broad coverage from the national press. Each of the teachers who participated in the national meeting went on to organise diabetes meetings in schools with the assistance of local authorities. In 2011, a one-day training meeting was organised across Turkey, which included teachers, government officials, and paediatric diabetes and obesity experts. By World Diabetes Day 2011, the entire campaign was launched and millions of school children and teachers joined the school training sessions that were organised within the scope of the programme and facilitated by diabetes health experts.

Awareness was further reinforced with a poster campaign, entitled, ‘Does my child have diabetes?’ and distributed to 60,000
schools across Turkey, reaching approximately 650,000 teachers and 16 million school children at primary and middle schools (figure 1). Two brochures on diabetes and obesity in childhood, a guide on diabetes care of the child at school and a training presentation for teachers were also provided. The Ministry of Education sent an official letter to provincial directorates about diabetes at school, and paediatric endocrinology clinics across the country developed a postal campaign directed to teachers and school administrators about caring for a child living with diabetes in the school environment. Film was utilized as a major component of instruction for the Diabetes Program at School and four short films covered topics such as diabetes care management, prevention of childhood obesity, and voices of children living with diabetes. A programme website offering education materials and other forms of media was launched (www.okuldadiyabet.org) to expand information and awareness across all of Turkey.

Impact of the Diabetes Program at School

By the end of 2011, over 7.5 million students, and nearly 600,000 teachers were trained in 25,000 schools by a variety of diabetes healthcare experts. Since the first training in 2010, a large number of additional students and teachers joined the school training activities. In 2012, ‘Teacher Achievement Awards’ were established and given to seven teachers, each from a different region of Turkey.

To the credit of the programme, 30 teachers who had undergone diabetes training helped detect early diagnosis of diabetes in 40 children.

Programme effectiveness evaluations were given before and after training to the teacher participants. After one initial survey, 85% of the surveyed teachers noted that they were satisfied with the diabetes education, 89% noted that the programme was informative about the symptoms of diabetes and, in another surveyed group, 99% of teachers found the website useful for retrieving relevant information. The results of the survey showed that the online education platform and website helped teachers understand the symptoms of diabetes and lead to increased awareness for early diagnosis. The teachers also reported greater understanding of the healthcare needs of students with diabetes at school, and the importance of healthy eating, such as avoiding junk food at school. To the credit of the programme, 30 teachers who had undergone diabetes training helped detect early diagnosis of diabetes in 40 children.

Acknowledgements

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Website: www.okuldadiyabet.org

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The role of diabetes tech youth: getting connected

Francine R. Kaufman
The use of diabetes technology by people with type 1 and type 2 diabetes is becoming increasingly widespread. Examples of the types of technology include devices that monitor glucose and deliver insulin, cell phone-based text messaging, applications (apps) on smart phones, and internet-enabled education and support programs. While some programs and devices are highly technical and expensive in terms of investment by the patient, family, and health care system, others are less complex and designed for popular usage. Perhaps the most exciting aspect of the use of technology for diabetes treatment, education, motivation, and support is how children and youth may particularly benefit from these interventions. As children and youth around the world grow up using a variety of technologies to learn, play and communicate, they will also be able to use the ever-increasing array of diabetes devices, on-line programs and engagement tools to improve their diabetes outcomes. This article describes the broad categories of diabetes technologies and suggests how they may positively impact paediatric and teenage diabetes populations.

Self-monitoring of blood glucose (SMBG)
Technologies that enable the measurement of blood glucose levels with a finger stick, referred to as SMBG, have been available on a widespread basis for over three decades and have been viewed as one of the greatest advances in the field of diabetes. SMBG is part of the Global Guideline1 for diabetes in childhood and adolescence, although those living in the most poorly resourced regions often do not have full access to medically necessary supplies. Beginning with the Diabetes Complications and Control Trial, referred to as the DCCT,2 there have been many articles in the world’s diabetes literature attesting to the value of measuring blood glucose levels throughout the day and night to improve glucose control in people with type 1 diabetes in all age groups, including children and youth. While the use of SMBG by the general type 2 population is still controversial, for youth with type 2 diabetes the value of SMBG has been highlighted by the results of the TODAY Trial.3 Youth with type 2 diabetes in this US study were shown to have high rates of co-morbidities and difficulty controlling their diabetes making it important for youth with type 2 diabetes to monitor glucose levels at home.

Improvements may give additional motivation to children and teens when it comes to the drudgery of accounting for daily blood glucose values in order to adequately manage their diabetes.

Over the years, manufacturers have developed improvements to glucose meters, glucose strips and lancing devices for the benefit of the paediatric diabetes population. Examples include: smaller lancets and meters; decreased time to get results; very low blood volume requirements; linkages to more intuitive retrospective data management displays via computer, internet and smartphone; and
connections to games and reward systems. These improvements have helped make SMBG easier to use and may also give additional motivation to children and teenagers when it comes to the drudgery of accounting for daily blood glucose values in order to adequately manage their diabetes.

**Continuous glucose monitoring (CGM)**

Continuous glucose monitoring (CGM), first implemented in the early 1990s, provides up to 288 glucose values in a 24-hour period through a sensor placed under the skin. The real-time CGM system displays data on a monitor or pump screen, and shows the latest glucose value, the glucose trend graph, and arrows indicating the direction and rate of change of glucose levels. Alerts are given when glucose levels reach, or are predicted to reach, pre-set high and low thresholds determined by the patient in collaboration with his or her diabetes health care team. There is also a CGM device worn for three to six days with the relevant blood glucose data only available for review once the sensor is removed.

CGM data can be uploaded into systems that display the data in a variety of ways (e.g., pie charts, graphs and tables), and in association with the patient’s simultaneous finger stick blood glucose values. If the CGM system is integrated with an insulin pump, the data in the pump concerning insulin delivery and carbohydrate intake can also be part of the CGM display. For CGM to be valuable, all this information should be used in the moment, or in retrospective analysis, to better balance insulin dosages, food/carbohydrate ingestion, activity levels and stress/illness when it occurs. To succeed, children and youth with diabetes and their caregivers must not only be taught CGM functionality, but also motivated to use it. The first big study using CGM in children, done with the support of the Juvenile Diabetes Research Foundation (JDRF), did not show a marked benefit from the use of CGM in improving HbA1c, mainly because the children in the study did not wear CGM enough of the time. However, in subsequent studies when CGM was utilised the majority of the time, children benefitted by improving their diabetes outcomes and parents benefitted by reducing their worry about hypoglycaemia.

In contrast to SMBG, the use of CGM remains less widespread globally for a variety of reasons including: cost; concern about patient acceptance, motivation and usage; limited places to put sensors on small children’s bodies; and limited numbers of global health care providers with experience in using CGM. While CGM is rarely available in low-resourced countries, some high-resourced countries and health care systems allow for almost unlimited use by paediatric patients living with type 1 diabetes while others have restricted its use to only those with specific indications, such as prior severe hypoglycaemic events, recurrent DKA, and high HbA1c results. The newer generations of CGM systems use smaller more accurate sensors for improved patient comfort and acceptance. Newer CGM systems are now driving the primary elements of the artificial pancreas through their linkage with insulin pumps. Second generation CGM systems may soon be able to move data in real-time for shared access from the child wearing the CGM to a remote caregiver thus helping to reduce patient burden and improve glucose outcomes. It is hoped that, as these systems evolve, access to CGM technology will be increased for all children and youth living with diabetes worldwide.

**Insulin pump therapy**

An insulin pump is a small mechanical device worn by a person with diabetes to deliver basal and bolus insulin through a small tube or needle placed under the skin. Basal insulin can be programmed to change throughout the day and night, and bolus insulin is given for food and to correct a high glucose level. Insulin pumps have been in use for over thirty years, have been studied extensively in children and have been shown to have benefit in improving glucose control and reducing hypoglycaemia when someone is switched from multiple daily injection therapy. In many high-resourced countries, pumps are used routinely in children and teenagers who are motivated to wear the device, willing to do frequent SMBGs or wear a CGM, and who may not be at glucose goal or have had a diabetes management problem. Insulin pump therapy is part of the basic care package in many regions, although main barriers for uptake are cost of the device and the need to have a well-trained and experienced diabetes education team. In addition to the cost of the pump and other durables, the routine recommendation that insulin pump therapy is best served by rapid-acting insulin analogues further increases
The artificial pancreas
The artificial pancreas is the term used to describe an insulin pump coupled with real-time CGM providing automatic delivery of insulin through closed-loop mathematical algorithms. The artificial pancreas delivers insulin based on sensor glucose levels. If the glucose level is high, more insulin is given, and if it is low, insulin can be automatically stopped. The accepted concept for the development of the artificial pancreas is that it will be accomplished through a series of steps, until all insulin delivery is done automatically, without input from the person or caregiver. The first step has the ‘threshold suspend’ feature that automatically stops insulin delivery at a pre-set sensor glucose level to minimize hypoglycaemia. The next step is to use a ‘predicted suspend’ feature so that insulin stops before hypoglycaemia occurs, which may help prevent hypoglycaemia from occurring altogether. There have been many research studies demonstrating promising results from the use of the artificial pancreas, including studies in older children and youth. It is hoped that when the full artificial pancreas is approved and released for medical use, it will prove to be a near ‘cure’ for type 1 diabetes.

On-line programs, applications (apps) and games
There are a variety of programs available on the internet and through mobile applications on tablets, smartphones and cell phones which can aid in type 1 and type 2 diabetes management and address obesity as a risk factor for type 2 diabetes. These programs range from simple text messages reminding the child or caregiver to perform various diabetes tasks, review educational and motivational online videos, utilise programs that track and analyse multiple data obtained manually or through connections with other devices, like pedometers, scales, and more. Glucose values, insulin doses, carbohydrate and calorie intake, physical activity levels and weight can be tracked and analysed, with supplemental treatment and behavioural suggestions and encouragement. In some instances, these applications have been linked to games and a broader on-line community to increase engagement and motivation so children will improve their behaviours and overcome their barriers to good care. The use of mobile applications, internet programs and games are potentially available for little cost with worldwide access. How much these programs will change the face of diabetes education, care and outcomes has yet to be determined.

Conclusion
There have been many advances in technology which have helped change how individuals manage diabetes, particularly benefitting children and youth. From glucose meters, to insulin pumps and CGM devices, to the soon-to-be-available early steps of the artificial pancreas, advanced technologies hold tremendous promise but remain restricted to high-resourced countries. The newer systems are expensive and require patient and health care provider education and commitment. On-line programs and cell phone applications have greater potential to be used by a broader range of patients, including those in low-resourced countries because they are often inexpensive and relatively easy to use. It is hoped that newer technologies will continue to motivate and help children and youth with type 1 and type 2 diabetes improve their health.

Francine R. Kaufman
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References


A quirky companion
Living with diabetes and controlling blood glucose (BG) can feel like trying to train a wild monster how to behave. At least that’s what Fredick Debong, Frank Westerman, Gerald Stangl and Michael Forisch thought when they began developing their companion application (app) ‘mySugr’. Based on two of the co-founders living with type 1 diabetes, the team had a personal understanding of the challenges associated with successful diabetes management including keeping track of glucose values, food intake and activities day-after-day without giving up. The adage, you don’t know where you’re going if you don’t know where you’ve been may sound like a tired cliché but for people who manage diabetes, life depends on keeping a record.

After two years of ideation and development, the mySugr team completed their ‘app with attitude’ complete with a giggling, snorting monster — ready for naming and eager to please with reactions that mimic diabetes highs ‘Ouchies!’ and lows ‘hippo 😊?’. First launched in Austria in 2012 and now available in 34 countries worldwide, mySugr is an electronic diabetes diary that utilises a game platform to motivate users to track their diabetes data in a fun, unconventional format.

Technology is well placed to help people manage a data driven condition like diabetes and there are many options to choose from for improved glycaemic control. Blood glucose meters are becoming smaller in size and more dynamic – giving glucose results in less than five seconds. Insulin pumps have been successful not only for the freedom aligned with more accurate dosing, but also for data memory and activity recall. Continuous glucose monitoring systems offer real-time blood glucose values and trends. One area that has never caught on in the diabetes tech sphere is a winning application for diabetes tracking and logging – until now. In this special report, Diabetes Voice introduces a new application that turns the task of monitoring diabetes into something more like a game helping children and adults overcome barriers to achieving their targets in a smart, playful format.

Doctors and other healthcare providers will appreciate the user’s ability to email customised PDF diabetes reports. Moreover, mySugr doesn’t judge the quality of glucose variability, but instead rewards the user for participating. Earned points are tallied for gold stars indicated on a progress bar letting users know how hard they’ve worked and when they have beat their diabetes monster! For further motivation, mySugr offers challenges that can even result in donations to non-profit diabetes fund-
raising and research organisations, such as IDF’s Life for a Child Programme, the Juvenile Diabetes Research Foundation, and the Diabetes Hands Foundation.

mySugr co-founder Fredrik Debong has been living with diabetes since four years of age and admits he was in a deep period of diabetes burnout before he began working seriously on mySugr. ‘I had a six-unit rule which meant I would inject six units of insulin before I drank a sugary soda or pizza — anything really. Obviously it wasn’t a workable strategy!’ Slowly with the help of his partner, Fredrik started to improve self-management behaviours by doing just one thing better a day. ‘Initially I told myself, “OK, this week, I will test every day, once a day”; and then if I achieved that goal I would reward myself or my partner would reward me like I might get a break from doing the dishes!’ Eventually Fredrik’s BG levels really did improve, but it wasn’t until he started competing with another acquaintance living with type 1 diabetes that the challenge/reward system hit him as a promising new way to get motivated. ‘During a vacation I competed with a friend also living with type 1 diabetes for the best BG result between us and we actually started enjoying our therapy,’ says Debong. This prompted him to consider the design of a similar app built on the premise that helping people achieve small simple steps with a challenge might work. Another objective of the team was to develop a system that moved away from fear as the primary motivation for meeting diabetes targets. ‘Many people living with diabetes are told they need to test and get good
results based on the feedback that if they don’t they will lose a leg or go blind. This doesn’t work,’ explains Debong.

The success of mySugr, which received a CE Mark for a class 1 medical device from European authorities and equivalent approval from the U.S. Food and Drug Administration (FDA), is evident by the ever increasing number of downloads it receives weekly. According to Kyle Rose, Managing Director for US Operations, mySugr had attracted 40,000 registered users by July 2013 making it one of the top diabetes management apps available today. One young adult from Maryland was so excited by the June launch of mySugr in the US that he tweeted ‘@mysugr makes it an awesome thing to have diabetes!’

**Introducing mySugr Jr**

Based on their 2012 success, the mySugr team decided to create a more simplified version for young children living with diabetes, calling it mySugr JR. Currently JR is only available in Austria and Germany, but soon it will launch in English for the US and Europe. Depending on a child’s skill level, entries for BG values, food and dosing can all be made with the push of a few buttons, and photo opportunities for high carbohydrate foods like an extra large piece of pizza are synchronized with a parent’s smartphone for assessment. Parents have less worry during school hours or extracurricular activities, and can give feedback at any time while keeping track of their child’s therapeutic decisions. Children feel more supported while simultaneously learning to be more independent.

*Diabetes Voice* had the opportunity over the summer to talk with mySugr users Sandra and Gerhard whose son Paul was diagnosed with type 1 diabetes two years ago. They were introduced to the mySugr app at an event for parents of children with type 1 diabetes, and decided to give it a try. Sandra believes mySugr gives her a greater connection to her son when he is away from home, ‘I get a message on my mobile phone and I can see how he feels, what he has eaten and how his blood glucose numbers have been,’ she explains. She also believes it has made her son more interested in caring for his diabetes.

At nine, Paul’s biggest complaint about having diabetes is that he can’t eat as much candy as he would like, but fortunately mySugr has helped him manage some of the most tedious aspects of diabetes. Paul named his mySugr monster Darth Vader, after the evil Star Wars villain, and appreciates how he can take photos of his food rather than write all the information out in a ‘boring diary’. What’s more, although mobile phones are banned from school, Paul is allowed to have his monster (via the mobile) in class, and his friends think that’s cool.

Elizabeth Snouffer
Elizabeth Snouffer is Editor of *Diabetes Voice*.

www.mySugr.com is a Vienna-based start-up founded in 2011 specializing in diabetes technology. Earlier in 2013, it opened an office in San Francisco alongside partner company Delta Project Management.

https://mysugr.com/
Children and diabetes: success and challenge in the developing world

Graham Ogle, Angie Middlehurst and Robyn Short-Hobbs

The International Diabetes Federation’s Life for a Child Programme was established in 2001 with support from the Australian Diabetes Council and HOPE worldwide. With secure sustainable funding, LFAC not only contributes monetary or in-kind donations to help children with diabetes in developing countries, but also provides medical training, education and mentoring for health professionals in under-resourced regions. Keeping up with the digital age, LFAC now offers support materials online in nine languages.

In the following feature, the LFAC management team presents current challenges and achievements connected to building stronger foundations of care for children most in need.

Imagine the courage of a mother in the Democratic Republic of Congo diagnosing her own sick child’s diabetes by tasting his urine because the child’s doctors have not yet considered a diagnosis of diabetes. Imagine the suffering of a 15-year-old with diabetes in Uzbekistan who has inadequate access to insulin resulting in recurring bouts of life-threatening ketoacidosis, making it impossible to attend school. Imagine the frustration of a parent to a five-year-old boy in India, who spends his entire savings on the promises of unlicensed doctors, only to see his son get thinner and sicker before his eyes.

These are just some of the very real challenges facing children, young adults, and families in the developing world; challenges countered by the International Diabetes Federation’s Life for a Child (LFAC) Programme. Type 1 diabetes is one of the most common, life threatening childhood diseases and currently affects approximately 490,000 children worldwide under 14 years, with a further 77,000 cases newly diagnosed every year. It is estimated that a similar number of young people aged 15-25 also live with diabetes.

Type 1 diabetes is one of the most common, life threatening childhood diseases.

Since 2001, LFAC has worked directly with established local under-resourced diabetes services to help provide the best possible health care for children and youth with diabetes. Depending on local needs and the supplies available to LFAC, supportive measures include insulin, syringes, blood glucose meters and test strips, HbA1c diagnostic tests, education materials, health professional training, capacity building and vocational training. Presently, more than 11,200 children and youth in 43 countries receive LFAC assistance.

Diabetes management is complex for patient and carer alike, requiring daily insulin injections and careful monitoring of blood glucose, food and exercise. A child diagnosed with diabetes in a devel-
Developing country faces obstacles unknown to their counterparts in the developed world. Insulin, blood glucose meters and test strips are either inaccessible, unaffordable, or both. Medical staff may be untrained in the diagnosis and treatment of childhood diabetes so complications develop early and quality of life is poor. To make matters more tragic, insulin is not available to all who need it even though the medication was discovered over 90 years ago and still remains the only life-sustaining treatment. Fear and uncertainty regarding vital supplies and the future are ever present.

**Insulin is the first priority, because a child with type 1 diabetes may die within a week without this life-saving necessity.**

To meet the needs of these children, young adults, and health professionals, LFAC collaborates with governments, diabetes associations, diabetes and community health services on various levels to build capacity and strong foundations of care. Challenges, including practical needs or barriers, vary from country to country. LFAC accomplishments include:

- **Shipping donated insulin to all countries participating in the Programme that request help.** Insulin is the first priority, because a child with type 1 diabetes may die within a week without this life-saving necessity. In 2012, 25 countries received LFAC shipments.
- **Overcoming numerous logistics and customs hurdles in the delivery process.** Once in-country, long road-trips are sometimes required to distribute the insulin. In Zimbabwe, diabetes association staff travelled 2,600 kilometres across ten provinces to distribute supplies.
- **Provisioning of donated blood glucose meters and test strips which has resulted in thousands of children, together with their families, learning to understand blood glucose readings, engaging in the treatment of diabetes, and appropriately adjusting insulin and food intake.**
- **Facilitation of doctor and nurse training, including distribution of educational materials, and technical or mentoring advice.** The International Society for Paediatric and Adolescent Diabetes (ISPAD) has proved to be a tremendous ally in the Programme’s drive to increase diabetes education of health professionals. Since January 2012, ISPAD members have conducted site visits in 16 LFAC-supported countries where local professionals were supported with diabetes training and mentoring. Most recently an ISPAD workshop in Azerbaijan trained 30 health professionals about the complexities associated with paediatric diabetes.
- **As additional support for children with diabetes, their families, and health professionals in less resourced countries, LFAC developed a website for free diabetes education materials in English, French, Spanish, Arabic, Tagalog (Filipino), Azeri, Vietnamese and Bahasa (Indonesian).** Materials such as ‘Professor Bumblebee’s Guide to Type 1 Diabetes’ DVD have been particularly useful in simplifying the complexity of diabetes for children through a fun, visual medium. Available on the LFAC YouTube Channel (http://www.youtube.com/user/LifeforaChild) in five languages, it was recently translated into Tajik.

Diabetes is a constant and unrelenting condition, and it is only through understanding and mastering the condition that these children can grow, mature, and lead a happy fulfilling life. The diagnosis of diabetes is daunting and frightening, and getting off to a ‘good start’ with simple, concise, and often repeated education sessions for the child and parents is essential for families to gain confidence in managing diabetes at home and at school.

A lack of understanding related to diabetes in the school setting can disrupt education, cause insecurity and inhibit children from reaching their full potential. A simple explanation of diabetes and its management, by parents or a health professional dispels myths and allays the fears of child, parent and teacher. Social exclusion and misunderstanding are par-
particularly distressing aspects of diabetes for children and youth. Adolescence can be a particularly trying time of change, uncertainty and rebellion because diabetes tasks intrude on day-to-day life, remove spontaneity and increase the feeling of being different and not fitting in with a peer group. Transition clinics specifically targeting this age group (16-25 years) can assist in maintaining contact with youth through clinic attendance, and encourage adherence to diabetes management. Prevention of young people falling into the ‘black hole’ only to emerge years later with diabetes complications is a challenge for health professionals worldwide.

Camps, or day activities if resources are limited, are widely acknowledged to be extremely beneficial to children and youth, enabling them to meet others with diabetes, feel less isolated and increase personal understanding and management of diabetes in a relaxed, non-threatening and fun environment. LFAC encourages the development of diabetes camp programmes, assisting financially where possible. It has been heartening to hear that in Ecuador, Haiti, Nepal and Rwanda, young people’s lives have been transformed by the experience of diabetes camp.

For children with diabetes, war or natural disaster not only threaten personal safety but also access to life-saving treatment. Families may be forced to flee their homes, losing contact with experienced medical staff and functioning health services, with no place to keep insulin cool or no access to the medication at all. During 2012, partner organisations Santé Diabète in Bamako, Mali, and Association des Diabetiques du Congo (ADIC) in Goma, Democratic Republic of Congo, experienced armed conflict firsthand. LFAC staff did an incredible job tracking and assisting children and families with essential medicines and clinical care as needed.

The LFAC Programme unifies the world’s diabetes network behind its vision ‘that no child should die of diabetes’.

When diabetes becomes unmanageable, young people may fail to complete schooling or find a job. In some countries, lack of social awareness around diabetes, combined with extreme poverty, diminishes marriage opportunities and can lead to social and economic isolation. In India, young women have been known to hide the fact that they have diabetes from their future husband.

Type 1 diabetes is a life-long condition affecting children and their families in a myriad of ways. Living with diabetes is difficult in any country, although children and youth in less-resourced settings face greater obstacles. LFAC exists to level the playing field, empowering children and young adults with diabetes access to the tools they need to live full and happy lives, and bolstering their hope of a bright future. On a global scale, the LFAC Programme unifies the world’s diabetes network behind its vision ‘that no child should die of diabetes’.

Graham Ogle, Angie Middlehurst and Robyn Short-Hobbs

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At ADA’s 73rd Scientific Sessions Graham Ogle was presented with the Harold Rifkin Award for Distinguished International Service in the Cause of Diabetes for his role in establishing and strengthening diabetes services in many parts of the developing world.

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Donations: http://www.idf.org/lifeforachild/donate

References

http://www.idf.org/lifeforachild
Clinical care

Type 1 diabetes accounts for approximately 10% of the total burden of diabetes in a population, but it is the most predominant form of the disease in younger age groups in most countries. Poor glucose control for the child living with diabetes (HbA₁c > 7.0%) is linked to severe diabetic complications later in life and early death. The goal of best standard practice for type 1 diabetes care is to mimic physiological insulin replacement as closely as possible and to achieve this there are two main therapeutic approaches: multiple daily injection therapy (MDI) or insulin pump therapy. MDI is the accepted standard of care for maintaining near-normal blood glucose to reduce the risk of complications, but evidence is mounting that MDI does not deliver optimal glucose control as effectively as insulin pump therapy. Proponents of pump therapy maintain that long-term benefits far outweigh the costs (USD 7000 for device and a minimum of USD 2500 per year for supplies) because pump therapy improves HbA₁c values and reduces the number of serious complications, thereby making investment in pump programmes a cost effective proposition to consider in addressing the burden of diabetes.

To shed light on the controversy surrounding best care practice for children living with diabetes, Diabetes Voice invited two experts to contribute their opinions for or against supporting guidelines that require insulin pump therapy as first-line treatment in paediatric type 1 diabetes care.
Type 1 diabetes, initially thought to be rare in Africa and other developing countries, has in the least quarter of the century become a major health challenge. It has been estimated that type 1 diabetes affects 19,000 people in the World’s poorest countries but due to the lack of reliable data on the disease in these countries, the true burden could be masked. The low prevalence of type 1 diabetes is a reflection of poor prognosis, low incidence and under diagnosis or misdiagnosis. Also, type 1 diabetes is likely to be one of the lower priorities of respective ministries of health in developing countries taking into consideration its lower prevalence and high costs.

In Tanzania, the average annual cost of care for a patient with insulin requiring diabetes has been estimated as USD 229 of which two thirds was for purchase of insulin. In another study in Tanzania, about 50% of the patients considered their disease as a major physical and psychological challenge and the monthly cost for an average insulin treated patient equaled 26% of the minimal wage.

Most of the countries in sub-Saharan Africa already have a large burden of communicable disease such as HIV/AIDS, tuberculosis and malaria. With a large percentage of the population living below the poverty line, there are major challenges ahead in managing the ‘double burden’ of communicable and Non-communicable Diseases. The major barriers to access to care for patients with insulin requiring diabetes in Mozambique and Zambia were interrupted insulin supplies and unaffordable costs, lack of standardisation of insulin syringes and interrupted supplies, the high costs and lack of consumables for diagnostic tools, a shortage of trained health care workers and the importance of traditional beliefs.

With the above background, offering insulin pump therapy to children and others with type 1 diabetes is a distant dream in the developing countries of sub-Saharan Africa. It could be affordable and accessible to the privileged few but for the majority the challenge is getting access to adequate multiple daily injections.

In order to achieve reasonable control of blood glucose in children aged less than 12 years old living with type 1 diabetes in the developing countries of sub-Saharan Africa, multiple daily injections is the way forward provided the challenges of ensuring access to insulin, syringes, monitoring tools and adequately trained health care providers can be overcome. Thankfully, there have been positive developments in improving this access to care for children with type 1 diabetes in these countries.

The International Diabetes Federation’s (IDF) Life for a Child Programme has been instrumental in initiating improved access to care for children with type 1 diabetes in several countries of the Third World. The Programme has facilitated the supply of insulin, syringes, and monitoring tools and the training of health care providers and education for children and their care-givers.

What is important – insulin pump, multiple daily injections or improved access to treatment?

Kaushik Ramaiya
Clinical care to both multiple daily injections (MDI) of insulin and insulin pumps or continuous subcutaneous insulin infusion (CSII), the insulin pump should be considered an important option for insulin delivery in type 1 diabetes.

The insulin pump remains the most physiological system of insulin delivery available today. Functioning beta cells in the pancreas of a person without type 1 diabetes release a small amount of rapid-acting insulin to the liver continuously (referred to as basal insulin) with a bolus of rapid-acting insulin released with meals to maintain blood glucose levels throughout the day. An insulin pump delivers insulin in a similar manner by infusing a small amount of rapid-acting insulin subcutaneously without the use of long-acting insulin analogs. A bolus of rapid-acting insulin can be administered shortly before meals to mimic the physiological insulin bolus. The ultimate goal of insulin administration in patients with type 1 diabetes should be to imitate the physiological release of insulin, as done by the insulin pump.

The insulin pump has been shown by meta-analyses and several independent studies to decrease glycosylated hemoglobin (HbA1c), total insulin dose, glycaemic variability and the incidence of severe hypoglycaemia when compared with MDI in patients with type 1 diabetes. However, the improvement in HbA1c and reduction in hypoglycaemia is most significant in older individuals with a longer duration of diabetes and with a higher baseline HbA1c. The insulin pump has higher patient satisfaction than MDI, possibly related to increased portability and improved ease of insulin dosing. Additionally, suspension of insulin infusion and sensitivity factors allow for improved control over insulin administration and modification of insulin dosing based on activity level, food intake and sickness.

Benefits of the insulin pump specifically for young children with type 1 diabetes include the ability to easily administer multiple insulin boluses without increased injections due to their high frequency and unpredictability of meal times and amounts, allowing for more accurate insulin dosing. Moreover, the insulin pump feature of predicting the amount of active insulin on board avoids ‘insulin stacking’ (injecting an insulin dose too soon after the previous dose thus increasing the risk of hypoglycaemia) as a result of frequent meals and frequent insulin dosing. Furthermore, the ability to apply multiple basal insulin rates and carbohydrate to insulin ratios are especially beneficial in children who frequently require differing insulin doses depending on...
the time of the meal or snack. Due to the pump’s ease in ability to modify the administered insulin dose, the insulin pump may be preferred when total insulin dosing naturally increases as insulin resistance rises during puberty.

Despite clear benefits of insulin pump therapy, it may not be the best option for all patients with type 1 diabetes. Patients may not be willing to perform an adequate number of blood glucose measurements daily, possibly due to cost and time purposes, which is important for safety. In addition, the insulin pump has the theoretical increased risk of diabetic ketoacidosis (DKA) secondary to pump failure. However, several studies have shown similar rates of DKA in both MDI and insulin pump users. Lastly, the cost of the insulin pump is higher than MDI. Disadvantages specific to children using an insulin pump include a limited amount of available sites to place pump catheters and greater sensitivity to the adhesive used in the infusion sets.

The ideal method of insulin delivery and continuous glucose monitoring would be a closed-loop system in which the amount of insulin injected is modified by continuous glucose monitoring data of the current glucose value and trends in glucose levels. Several previous small, non-randomized clinical trials done in Europe utilising insulin pumps equipped with a Low Glucose Suspend (LGS) function have shown a significant decrease in hypoglycaemia without rebound hyperglycaemia or a change in HbA1c. Two recently completed large, randomised clinical trials (both In-Clinic exercise-induced hypoglycaemia and In-Home) ASPIRE (Automation to Simulate Pancreatic Insulin Response) studies, have shown that a Low Glucose Suspend feature in sensor-augmented insulin pump therapy, the first step toward a closed-loop system, demonstrated a decrease in hypoglycaemia without a change in HbA1c. Sensor-augmented insulin pumps equipped with LGS are available in Europe and many other parts of the world, but the LGS function has not been given FDA approval in the United States.

In conclusion, while MDI is a viable option for insulin delivery, we believe that the use of insulin pumps should be considered for patients with type 1 diabetes as it imitates the physiological release of insulin, decreases hypoglycaemia and HbA1c and is a first step towards the ideal emerging diabetes management technology — a closed-loop system. Important consideration to individual situations should be given prior to determining the most appropriate insulin administration method for patients diagnosed with type 1 diabetes.

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References

Managing a chronic illness can be challenging, and developing effective coping strategies to overcome difficulties is essential for maintaining health, balance and happiness. Type 1 diabetes is one of the most common chronic illnesses of childhood and requires a complex and demanding treatment regimen. While the large majority of childhood diabetes is type 1, there are increasing numbers of adolescents with type 2 diabetes who, requiring a similar treatment regimen, are subject to comparable risk factors for stress. Frequent administration of insulin, checking blood glucose levels, and treating high and low blood sugars are all a part of daily life with diabetes. Children with diabetes and their families must also coordinate these tasks with dietary intake and physical activity. Other aspects of diabetes management include attendance at regularly scheduled diabetes care appointments in clinics and hospitals, monitoring risk and treatment for medical complications and actively supporting a healthy immune system in order to prevent infections. These tasks are demanding and can be disruptive and stressful, illustrating how children living with diabetes and their families have a number of stresses that children living without diabetes do not experience.

Living with diabetes can feel overwhelming for parents and children because constant vigilance is required for proper care. Childhood diabetes means that no food is supposed to be consumed without understanding: the carbohydrate level, how much insulin to take, waiting for an effect, and problem solving if numbers are too high or low. Additionally, as children age, there may be social functions that they may miss altogether or participate in a limited fashion because of their condition. For example, some children are excluded from friends’ sleepovers, birthday parties, and summer camps because of fears from other parents and adults. Parents of children with diabetes may feel obligated to educate their child’s school at the beginning of the year, and advocate throughout the year by speaking with teachers, principals, and school nurses. Many children report feeling singled out and different from their peers. There is a range of reported experiences: some children have a network of very supportive friends and classmates, while others are bullied and teased.

In addition to these obvious stresses, there are also more subtle difficulties that often include family stress. Often in young children, it is the parents who are managing the child’s diabetes and, therefore, parental roles often include reminders about and supervision of all diabetes related tasks. Parents work very hard to promote development as with any other child while maintaining safety and health now and in the future. Even so, children can report feeling that parents ‘nag them’ or chastise them more than siblings. This can lead to increased arguments and tension between parents and youth. There can also be tensions with siblings, and the feeling that parental concerns are all centred on the child with diabetes.
studies of quality of life, family members report limitations and anxiety related to living with someone with diabetes. For all of these reasons, it is no surprise that children with diabetes have a higher risk of developing depression, anxiety, and psychological challenges than children without diabetes.

Children with diabetes experience higher rates of depression and other emotional problems than the general population. Specifically, about 15-25% of adolescents with type 1 diabetes experience depression compared to 14.3% in children without a chronic illness, which translates into a rate 2-3 times that found in the general adolescent population. Recent reports also suggest that youth with type 2 diabetes are at equal risk if not higher risk than youth with type 1 diabetes for these psychological challenges.

Depressive symptoms are particularly worrisome in youth with type 1 diabetes, given that on the lower end of risk these symptoms are related to poor self-care and on the higher end of risk are related to suboptimal glycaemic care and even recurrent diabetes hospitalizations.

One possible link that explains why depressive symptoms are related to poorer diabetes health outcomes is through self-efficacy. Those with higher depressive symptoms have lower self-efficacy, or the belief that they cannot control their diabetes. If you feel a lack of control it can lead to making unhealthy decisions because you feel that whatever you do, it will not change the outcome. Finally, depression and depressive symptoms not only relate to negative disease outcomes, but are also related to poor overall functioning and low perceived quality of life. Signs of depression can include sadness, apathy, distractibility, lethargy, sleep disturbances, appetite changes, low motivation, not participating in previously enjoyed activities, and thoughts about suicide. For young children, other common symptoms of depression are irritability, anger, tantrums, and aches and pains such as stomach ache or headache. When these occur it is important to talk with a health care team about them. In some cases, families may need to seek out mental health services to talk more thoroughly with a professional who can help develop positive coping strategies.

For people with diabetes, there is also the risk of developing diabetes distress, which includes negative feelings that are directly related to diabetes. For example, feeling extreme frustration with blood sugars, feeling bogged down by all the daily management tasks, or feeling isolated in the diabetes experience. Prolonged diabetes distress can lead to ‘diabetes burnout’, a term used to encompass the feeling of being unable to cope with diabetes. There may be other general depressive symptoms, or the feeling may be solely related to diabetes. With diabetes distress, patients are at increased risk of poor coping skills, poor problem-solving skills and poor self-care. These are the fundamental building blocks toward successfully navigating both diabetes management and other stresses that arise; therefore successful coping skills need to be fostered. Diabetes burnout is less likely to occur when a person feels supported by those around them, talks regularly to his or her medical team about these feelings, and is connected with other children and families with diabetes.

Although less prevalent than depressive and distress symptoms, there is evidence that children with diabetes are also at elevated risk of anxiety symptoms and have rates estimated between 13-17%. Anxiety can negatively impact children and their families in various ways. Fears of specific diabetes events like future hypoglycaemic episodes can contribute to heightened levels of stress and general anxiety overall. Parents also lose a great deal of sleep checking overnight blood sugars and worrying about trends toward lows. For the person living with diabetes, any level of increased anxiety is negatively related to the quality of glycaemic control, making diabetes self-management more difficult. Constantly worrying can weigh on children, and at worse, can lead to feeling helpless and being unable to manage diabetes. When children or
parents voice worries about diabetes, whether they seem reasonable or not, they should be heard. Sometimes a worry can be addressed through more education and sometimes a concern needs the help of a trained mental health professional. However, listening to parents and children and validating their concerns and worries is an excellent first step to reassuring them that diabetes can be managed and people with diabetes can thrive in life.

The presence of diabetes in a child’s life can increase risks for stress and distress.

Although these risks do exist, it is important to note that by and large, children with diabetes are resilient. Studies have found that after an initial spike in psychological problems following diagnosis, by 12 months post diagnosis, many of the symptoms have alleviated. Another group followed children six years post diagnosis and found that on average negative symptoms increased directly after diagnosis, but these symptoms largely dissipated after a year. Following this, some symptoms did increase again with greater duration of disease shown with a moderate elevation of depressive symptoms for both boys and girls and an increase in anxiety for girls. However, during this six year period, the average levels of symptoms were lower than the means reported for normative samples, and lower than cut offs for clinically significant diagnosis. There are specific things that can improve resilience in children with diabetes: increasing communication in the family can lead to more perceived emotional support and empathy from parents, leading to more positive interactions. Social support is also another important factor. When people in their social circle like teachers, friends, and extended family understand and support diabetes management, this can buffer potential barriers like discomfort associated with administering insulin.

In summary, the presence of diabetes in a child’s life can increase risks for stress and distress in the child and family. These stresses should be assessed and programmes should be in place for their prevention and treatment if they arise. Working alongside a psychologist or social worker with advanced training in diabetes can be a major help to children and families. However, listening to families and validating and addressing their concerns will always remain the first step in helping families achieve a balance with diabetes and thriving.

Diana Naranjo and Korey Hood
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Suggested Reading

References
Caregiver reports of provider recommended frequency of blood glucose monitoring and actual testing frequency for youth with type 1 diabetes

Joyce P. Yi-Frazier and colleagues for the SEARCH for Diabetes in Youth Study Group

Authoritative, evidence-based recommendations suggest that children and adolescents with type 1 diabetes should monitor their blood glucose regularly and frequently (four times per day or more) but how feasible is this, socially and financially particularly in low resource societies or when families have to foot the bill themselves? This article is reproduced as published in Diabetes Research and Clinical Practice (DRCP) (2012) with the full list of authors, abstract, statistical methods, tables, acknowledgments and references available via the DRCP website. The setting is a multi-center study from the USA. Future issues of Diabetes Voice may explore these questions further in less well-resourced environments.

Frequent blood glucose monitoring – a cornerstone of diabetes management

Given the complexity and demanding nature of modern-day treatment regimens for type 1 diabetes, it is not surprising that reported adherence to treatment recommendations among youth with diabetes is low, particularly among adolescents. Understanding the factors that are related to adherence is critical. Studies have clearly demonstrated that persons with higher levels of adherence to their treatment regimens have better glycemic control. Since sub-optimal glycemic control is associated with an increased risk for the development of diabetes-related complications, youth with type 1 diabetes should strive to achieve and maintain good glycemic control, even at an early age. However, optimal glycemic control in youth is not often achieved, particularly by older youth.

Based on the findings of the Diabetes Control and Complications Trial, frequent blood glucose monitoring (BGM) has become a cornerstone of optimal diabetes management. Adherence to frequent BGM has been found to be an integral factor in achieving optimal glycemic control. Greater BGM has been reported to be associated with younger age and insulin pump use. In most cases, a linear increase in BGM per day resulted in improvements in glycated hemoglobin (A1c), but recent analyses have suggested that this effect may peak at 5 times/day.

While previous research has shown that BGM is an important contributor to glycemic control, little is known about whether BGM by children with type 1 diabetes corresponds with the frequency of BGM recommended by their health care providers. Using data from
the SEARCH for Diabetes Study, these analyses explore demographic, family and clinical characteristics associated with provider recommended frequency of BGM, actual frequency of BGM, and concordance between these categories in children with type 1 diabetes as reported by child’s caregiver. Additionally we explore the associations between recommended and reported frequency of BGM and A₁c measurements.

SEARCH for Diabetes in Youth is a multicenter study that conducts population-based ascertainment of youth with clinically diagnosed, non-gestational diabetes who are <20 at the time of diagnosis. SEARCH has enrolled youth newly diagnosed with diabetes from 2002 through the present. Cases are ascertained from geographically defined populations in Ohio, Colorado, South Carolina and Washington, Indian Health Service beneficiaries from four American Indian populations, and enrollees in several health plans in California and Hawaii. Youth whose diabetes is not secondary to other conditions are invited to a SEARCH study visit. After obtaining informed consent and assent, physical measurements and fasting blood samples are collected from metabolically stable children, and questionnaires are administered. Youth whose diabetes was incident in 2002 through 2005 and who completed a baseline study visit were invited to return for follow-up visits.

The data included in this analysis are from children with type 1 diabetes who were 10 through 17 years of age and their parent/guardian (‘caregivers’) who accompanied them at their 24-month SEARCH follow-up visit where questions about their child’s provider recommendation for frequency of BGM and their child’s actual frequency of BGM were asked. The response rate for this follow-up visit was 52%. Of the 390 participants who completed a follow-up visit, 94% (n = 385) completed the survey which included the questions about BGM.

**Measures studied**

**included demographic, clinical and metabolic variables.**

Demographic variables included age at study visit, sex, race ethnicity, and insurance status. Insurance was categorized as private, state-funded (Medicaid/Medicare, etc.), other (which included student health clinics, military, Indian Health Services), or none. Family variables included family income which was categorized as <$25K, $25–49K, $50–74K, $75K+, do not know/refused, and family composition which was categorized as 2-parent household, 1-parent household, or other/unknown composition.

Clinical variables included duration of diabetes since diagnosis, insulin regimen, depression, and glycemic control. Duration of diabetes was the length of time between date of diagnosis and the 24-month visit. Insulin regimen was categorized as (1) basal-bolus using the insulin pump, (2) basal-bolus with glargine plus rapid-acting insulin, (3) multiple daily injections (MDI) with ≥3 injections/day, using glargine plus more than/ or other than rapid-acting insulin type, (4) MDI with ≥3 injections/day, using any insulin types excluding basal insulin, or (5) 1–2 injections/day, excluding glargine. Detemir and glulisine were not in clinical use during the data collection period. Depression was assessed based on the child’s responses on the Center for Epidemiologic Studies Depression scale (CES-D). This 20-item scale is a
Study participants are recently diagnosed young people with type 1 diabetes.
commonly used measure of depressive symptomatology in children age 10 years and older.\textsuperscript{13,14} For these analyses, we categorized the scores as minimally (0–15), mildly (16–23), and moderately/severely (24–60) depressed mood.\textsuperscript{15,16}

Glycemic control was assessed using blood samples shipped to a central laboratory (Northwest Lipid Research Laboratories, Seattle, WA) for analysis. An ion exchange unit (Variant II; Bio-Rad Diagnostics, Hercules, CA) quantified the glycated hemoglobin (A\textsubscript{1c}) levels. Optimal age-specific goals for A\textsubscript{1c} in children are <8.0\% for 10–12 year olds, and <7.5\% for 13–18 year olds.\textsuperscript{16}

The frequency of blood glucose monitoring recommended by the child’s provider as reported by the caregiver/parent – key data collected.

Caregivers of children with type 1 diabetes were asked to report the frequency of BGM recommended by their child’s health care provider and the number of times per day their child conducted BGM over the last three months. Response options for both questions were 6 or more times daily, 4–5 times daily, 2–3 times daily, at least once daily, or do not know. Adherence to recommendations was determined by comparing their responses to questions about recommended and actual BGM frequency, and categorized as exceeded (child monitored more than recommended by provider), met (child monitored exactly as the provider recommended), or did not meet (child monitored less than what the provider recommended) their child’s provider recommendation for daily BGM.

Detailed statistical analysis methods are given in the link as are the results tables. Table 1 shows the demographic, family and clinical composition of the 390 eligible children with type 1 diabetes. They ranged from ages 10 to 17 (mean ± SD = 14.0 ± 2.3 years) with a mean diabetes duration of just over 3 years (37.4 months). About half were female (48\%) and 74\% were NHW. Youth 13–15 years had the highest mean A\textsubscript{1c} values (9.2 ± 1.9 for 13–15 year olds, 8.4 ± 1.5 for 10–12 year olds, and 8.7 ± 1.8 for 16–17 year olds; p = .003) and were least likely to be in adequate control based on their A\textsubscript{1c} value (15\% of 13–15 year olds, 41\% of 10–12 year olds, and 27\% 16+ met the goal; p < .001). Other demographic, clinical, and family characteristics did not differ significantly by age (data not shown).

A fifth of caregivers reported that their child’s health care provider recommended blood glucose monitoring six times a day – every day. This advice varied considerably from centre to centre and according to a number of characteristics of the person with diabetes and their families.

Of the caregivers surveyed, 26\% reported that their child conducted BGM at least 6 times/day, 52\% 4–5 times/day, 16\% 2–3 times/day, and 6\% reported fewer than 2 times/day (Table 2, n = 2 with missing data). There was no significant difference between participant responses by study center (data not shown). Caregivers of younger children, those from two parent households, those with higher incomes, those who were NHW, and those on an insulin pump were significantly more likely to report being told to conduct BGM at least 6 times/day (Table 2). Additionally, caregivers of children who met their A\textsubscript{1c} goal were more likely to report being told to check more frequently than those who did not meet their goal. The child’s gender, health insurance status, duration of diabetes and depression scores were not associated with caregivers’ report of providers’ recommendations.

Higher family incomes and better glycaemic control were associated with more frequent blood glucose monitoring.
pump were more likely to report that their child conducted BGM at least 6 times/day (Table 2). Additionally, those children who met their $A_{1c}$ goal were more likely to have caregivers who reported that they conduct BGM more frequently than those who did not meet their goal. There was no association between frequency of BGM and child’s gender, health insurance status, duration of diabetes, or depressive symptoms.

$A_{1c}$ was significantly lower for children whose caregivers reported that providers recommended BGM at least 6 times/day compared to those who reported that their providers recommended BGM 4–5 times/day, or fewer. $A_{1c}$ values were also significantly lower for children who reported that providers recommended BGM 4–5 times/day compared to those who reported that their providers recommended BGM less than 4 times/day. Adjustment for age and insulin regimen did not change these results (Table 3, top).

$A_{1c}$ also varied significantly by the number of times caregivers reported that BGM was conducted (Table 3, bottom, p < .001). Youth with caregivers who reported their child conducted BGM at least 6 times a day had significantly lower $A_{1c}$ values than those who reported BGM fewer than 6 times a day; those who performed BGM 4–5 times/day had significantly lower $A_{1c}$ values than those who conducted BGM fewer than 4 times/day. Adjustment for age and insulin regimen did not change these results (Table 3).

We then compared caregivers’ report of provider recommendations for BGM to their report of their child’s frequency of BGM. While most of the caregivers (92%) reported being told by their children’s providers to conduct BGM at least 4 times/day (4–5 times or 6+ times/day), only 78% reported checking that frequently. Table 4 shows that adherence to recommended monitoring frequency was reported by 62% of the caregivers with 24% reporting they test less frequently than recommended and 14% reporting they test more frequently. Of 10–12 year olds, 92% met or exceeded provider recommendations versus 72% of 13–15 year olds and 61% of >16 year olds (p < .001). Those with private insurance reported meeting or exceeding provider recommendations more than those without (79% versus 65%, p = .01), and those who met $A_{1c}$ goal reported meeting or exceeding provider recommendations more than those who did not (91% versus 68%, p = 0.01).

A quarter of the participants test less frequently than recommended but 14% test more frequently than recommended.

In the adjusted analysis using multivariable logistic models, age (odds ratio [OR] = 8.6, 95% confidence interval [CI] = 3.8–19.6 for 10–12 year olds and OR = 1.4 (CI = 0.8–2.5) for 13–15 year olds, relative to > 16 year olds), private insurance (OR = 2.8, CI: 1.3–6.2), and $A_{1c}$ Exceeded = 8.6 ± 1.4, Met = 8.5 ± 1.6, Did not meet = 9.7 ± 1.9; p < .001) predicted meeting or exceeding provider recommendations. Gender, family income, household composition, duration of diabetes, insulin regimen or depression scores were not significantly associated with reported adherence to recommended monitoring frequency.

These findings demonstrate that, among a large diverse sample of children with type 1 diabetes, most caregivers (92%) reported being told by their child’s health care provider to conduct BGM at least 4 times/day. However, only 78% reported that their child monitored that often. Children whose caregivers reported that they monitored more frequently had lower $A_{1c}$ values. Although causality cannot be determined from these cross-sectional data, previous reports have shown the detrimental effect of poor adherence to BGM monitoring recommendations on $A_{1c}$.

Specifically, increased adherence has been associated with lower $A_{1c}$. Thus, our results reinforce the notion that BGM is strongly associated with glycemic control in children with type 1 diabetes.

One previous study reported that increasing BGM frequency to greater than 5 times a day did not result in further improvement of $A_{1c}$. In contrast, our findings suggest that those who reported checking at least 6 times/day did better than those who checked 4–5 times/day or less. Given this finding, it is interesting that only 22% of caregivers reported their provider recommended to check BGM 6 or more times per day. While frequency of provider recommendations did vary across study sites, no site differences were found in reported behaviors. In fact, compared to the percentage of caregivers reporting their provider recommended BGM >6 times/day, a slightly larger percentage of caregivers (26%) reported their child actually monitored that often. More attention to the accuracy of the ‘tipping out’ factor cited by Ziegler et al’s study and factors that may be involved in checking more than prescribed would be valuable, and may also have insurance policy coverage implications for BGM supplies.
Differences in age were particularly noteworthy as there was a significant difference in reported adherence to provider recommendations between the youngest and oldest children: only 60% of 16–17 year olds met or exceeded provider recommendations for BGM, compared with 93% of 10–12 year olds. These results are consistent with other studies which have demonstrated that older children with diabetes have poorer adherence to diabetes treatment than younger children.\textsuperscript{18,19}

We also found that NHW participants reported being told to BGM more frequently than other race categories. While this study is not able to determine whether this is based on caregivers’ perceptions or actual provider behavior, this finding may support growing literature showing racial disparities in diabetes outcomes,\textsuperscript{20} and specifically corroborates reports indicating a disparity in regimen intensity for minority youth with type 1 diabetes.\textsuperscript{21} In addition, those on an insulin pump were more likely to report more frequent monitoring. This supports the findings of Cortina et al.,\textsuperscript{22} who also found that insulin pump users reported higher BGM than those on multiple daily injection regimens. Clearly there is a need to better understand the clinical implications, potential selection bias, and disparities that may exist surrounding intensity of the BGM recommendations children receive as well as their adherence behaviors.

There were several limitations to this study. Causality cannot be established from cross-sectional analyses. Participation in the follow-up visit was sub-optimal, which may compromise the generalizability of these findings; for example, previous findings from the SEARCH study found that older children were less likely to participate in SEARCH study visits than younger children.\textsuperscript{23} However, of the participants, response rate to the survey was high (94%). Further, the provider recommendations assessed and the actual frequency of BGM were both based on the report from the children’s caregiver which was the parent or guardian who accompanied them to the study visit. We do not have their health care providers’ report of their actual recommendations nor a confirmation of the actual frequency of BGM from either the children with diabetes or from downloading their meter as these measures were not collected as part of the study protocol. We therefore cannot be sure whether these reports, particularly those for the frequency of BGM, may accurately reflect their actual frequency of BGM, particularly among older teens who are more likely to be responsible for their own care. However, caregivers’ recall or understanding of these recommendations, in particular, may be as important as what was actually recommended. It is reassuring to know that most caregivers report that health care providers recommended BGM at least 4 times/day. It is acknowledged that the caregiver report of actual BGM frequency may be overestimated. However, given the discordance reported between the provider recommendations and actual BGM frequency and the significant associations found with A1c, we can be somewhat confident that these results, if inaccurate, may actually be conservative. Strengths of the study include sample size and the ethnic and geographic diversity of the children in the SEARCH study. In addition, measurement of A1c was consistent across centers and over time through the use of a single laboratory.

The need for age-specific interventions which focus on improving diabetes self-management is well-established.\textsuperscript{24,25} Understanding the demographic and clinical characteristics of children associated with adherence to BGM may elucidate the groups most at-risk for poor management and subsequent poor outcomes later in life. Targeting interventions to groups identified in this study who reported not knowing, or not following, these recommendations may be useful for clinicians aiming at improving glycemic outcomes in children with type 1 diabetes.

Although results are consistent with other studies there are limitations to what can be concluded.
GOING BEYOND
THE EXPECTED IN
DIABETES MANAGEMENT

We are committed to developing personalized solutions integrated across therapies, devices and services. Partnership is our path to achieving this goal, enabling people with diabetes to make the most of life everyday.

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Encouraging healthy futures for Brazil’s children

ADJ - Associação de Diabetes Juvenil
Associação de Diabetes Juvenil - ADJ reports on the status of child health in Brazil over the past 20 years and discusses what types of programmes they and the federal government have developed to quell the obesity, diabetes and Non-communicable Disease epidemic faced by families and school aged children. Learn how ADJ is promoting diabetes education for families and making a difference in their quality of life.
NCDs represent health problems of the greatest magnitude, corresponding to an estimated 72% cause of death in Brazil.

Global childhood obesity has increased in the last three decades and has become a major public health problem. The International Obesity Task Force (IOTF), in 2005, estimated that 155 million children worldwide were overweight or obese.¹

Childhood obesity in Brazil, demonstrated in the Household Budget Survey (POF) of 2008-2009 and conducted by the Brazilian Institute of Geography and Statistics (IBGE) in partnership with the Ministry of Health Research, showed a significant increase in the number of overweight children in the country, mainly in the age group between five and nine years.²

The number of overweight children in Brazil more than doubled between 1989 and 2009, from 15% to 34.8%.

Moreover, the number of overweight children in Brazil more than doubled between 1989 and 2009, from 15% to 34.8%, respectively. The number of obese children has increased by over 300% in the same age group, ranging from 4.1% in 1989 to 16.6% in 2008-2009.²

The federal government of Brazil, pressured to provide solutions, considers public schools the cultural nexus or institutional centre point of education and health as well as a space where the protection, care and full development of the school community is established. Brazil’s Ministry of Health and Ministry of Education is responsible for coordinating education and health programmes with the objective of improving the quality of life for children, young adults and families. Once officials recognized the need to improve health education in Brazilian public schools, the federal government instituted the School Health Programme (PSE) in December 2007, established by Presidential Decree No. 6.286/2007. According to the Ministry of Education, public school attendance in Brazil constitutes 26% of the population for basic education, a percentage which represents early childhood education, elementary education, secondary education, vocational education and education for youth and adults.

The PSE was established to promote health and to educate students about health care in general, especially targeting health disparities or vulnerabilities that compromise the full development of children and youth in public schools. The PSE also takes into account varying geographical characteristics and culture, and aims to respect diversity and local customs, when initiating proposals or programmes. Specific actions of the PSE include clinical and psychosocial activities to promote health and prevent diabetes in society.
Recently, the Ministry of Health issued the Strategic Action Plan against Non-communicable Diseases (NCDs) in Brazil, 2011-2022. The development of the Strategic Action Plan was fortified with additional intelligence by education and research institutions, various Brazilian government ministries, health NGOs, medical entities, associations with chronic diseases, and others.

Nutrition in Action aims to decrease the risk of obesity and NCDs, such as diabetes, and has reached 45,237 students, aged 6-18 years.

Between November 2009 and September 2012, Associação de Diabetes Juvenil (ADJ), in partnership with the World Diabetes Foundation (WDF), developed a public school educational programme for the prevention of obesity in children and adolescents, called ‘Nutrition in Action’. Through nutrition education and by encouraging physical activity, ‘Nutrition in Action’ aims to decrease the risk of obesity and NCDs, such as diabetes, and has reached 45,237 students, aged 6-18 years old in 87 public schools in the state of São Paulo. It is noteworthy to report that in one student population of 6,589 surveyed, 16% (1,031) were overweight and 14% (903) were obese, highlighting the problem of childhood obesity in the region.

Additionally, ADJ develops specific activities and programmes for school aged children living with diabetes including initiatives like ‘Day by Day Kids,’ summer camps and counselling groups to promote the exchange of nutrition and health knowledge, thereby encouraging kids to better care for themselves and their diabetes.

Advocacy also plays a significant role in ADJ. Parents involved with ADJ are encouraged to unite and acknowledge the issues related to diabetes and to demand the Brazilian government's help to assist families struggling to live with and manage diabetes now and in the future. Rights for the child living with diabetes are also very important — ADJ helps to integrate children living with diabetes in schools, teaching the school to deal with diabetes and minimizing uncomfortable situations that school children with diabetes often face. ADJ assigns diabetes educators to clarify basic diabetes care and nutrition in the school, and promotes professional healthcare skills in different regions, with the aim of preparing carers for the specialized needs of people living with diabetes.
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watch our motivational video

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India

Took 1,500 steps on March 15, 2013
Their total number of steps as of today is 3,500

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Help us reach 371,000,000 STEPS

MARIA from Portugal took 3,500 steps in total

http://steps.worlddiabetesday.org
Taking type 1 diabetes to school is the subject of the second instalment for our Voices of type 1 diabetes series which features first person accounts of people living with either type 1 or type 2 diabetes and their perspectives on managing the conditions in our world today.

The child who has been diagnosed with type 1 diabetes depends upon school policies and a supportive environment to help manage the rigours of an individualised self-management regimen. In order for every child with diabetes to thrive, collaboration between the student, teachers, parents, school administrators, and health care providers is critical to ensure the condition is managed appropriately and safely.

All children living with type 1 diabetes require the freedom to manage diabetes in a school setting by monitoring their blood glucose, eating the necessary or appropriate foods, and administering insulin. At a minimum, having access to medically necessary devices and medicines such as needles, insulin pumps and pump supplies, insulin vials or pens, glucose, and various types of monitors in school is essential for health. The right to convey the seriousness of diabetes to others, manage the condition properly, resolve misunderstanding or discrimination firmly, and progress academically is key for success. No child should shoulder the burden of diabetes alone.

In the following features, students from four very different regions – Tanzania, India, USA and Brazil – speak out to discuss the ups and downs of what it’s like to take type 1 diabetes to school.
Self-acceptance is key

Anita Bulindi is an 18-year-old living in Dar es Salaam, Tanzania who has one more year of high school before she graduates. Anita has been an IDF’s Life for a Child (LFAC) Programme beneficiary since 2002 and is eager to share her journey about living with type 1 diabetes. Here she talks about life with diabetes at school and how it wasn’t until she accepted her condition that things started moving in the right direction.

In 1999, I was diagnosed with type 1 diabetes at the Hindu Mandal Hospital in Dar es Salaam at age four. I started school when I was three years old, so I was already going to school when I was diagnosed.

In 2002, I moved from the Hindu Mandal clinic to Muhimbili National Hospital diabetic clinic where I received insulin, a glucometer and all the necessary glucose-monitoring facilities free of charge, through IDF’s Life For a Child (LFAC) Programme. I am most grateful for this Programme.

It was very difficult to manage diabetes when I was younger and at school. I didn’t want to take care of diabetes. I wanted to eat biscuits like all the other children. So I kept the disease to myself. Only one or two friends knew about my condition and they scolded me when I ate treats. Once I had a hypoglycaemic episode in class and I wasn’t aware of what I was doing. It was quite embarrassing. When I was nine years old, I got malaria and it was so bad that I went into diabetic ketoacidosis (DKA). I used to miss school a lot during that time, but I don’t anymore.

I had a hard time with diabetes until I was in seventh grade because that’s when I started opening up about my condition. When I began to accept diabetes, I was able to better learn how to control it. Opening up to people made a huge difference, and around the same time, education, awareness and access to better doctors and clinics improved for me.

All my classmates began to understand my disease when I finally told them about my diabetes and afterwards, they became more supportive. Now, friends and classmates can recognize the signs of hypoglycaemia and they help me. My teachers at school are very supportive and everyone understands that I have a serious but manageable condition. My friends always accompany me to the nurse if I need help and have since I was in primary school.

Today, I am in form six at Shaban Roberts Secondary School and next year I will graduate. Currently, I take four injections a day and sometimes more especially when I need to correct a high glucose. I am able to snack as much as I want at school and I eat my lunch at home, so most of my injections are done there and not at school. I test my blood glucose with a blood glucose meter at my desk. I am usually aware of hypoglycaemia or high blood sugar because of the symptoms, like when I am feeling weird, weak, sweaty, cold, shaky, dizzy, have a bad headache or feel nauseated. My last HbA1c result was 8.1%, but my doctor says it should be better. I’m working on it! I have my own meter so I can test before and after I swim or play football. I test whenever I need to.

‘My parents trust my ability to make decisions on my own now but they will never stop worrying about me.’

My parents have always been worried about me and questioned everything about my day at school. When I was in ninth grade they finally allowed me the opportunity to stay overnight with girlfriends or to going out for fun. They trust my ability to make decisions on my own now, but they will never stop worrying about me. For my future, I am looking forward to independence, continuing my education and studying law at university. Law has been in my family for many years led by my grandfather who was a Tanzanian judge.’

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Diabetes in Society

My day begins with the routine blood sugar test done by my mother when I am half asleep. This blood glucose testing is done four times a day prior to every meal. The insulin injections were most dreaded initially but now I am comfortable doing it on my own. After a healthy breakfast at home, I look forward to the school bus ride with my friends although it is very crowded.

'I love eating candies and French fries, but I try to avoid them.'

At school, the teachers and my friends are well aware of my diabetes and I am fine discussing anything about my medication and dietary pattern. Snacks and lunchtime are difficult as my friends get a lot of treats, which are mostly denied to me because I have type 1 diabetes. Once or twice a week, my friends and I have a bus party on the way back from school which makes my mother worried as everyone gets junk food. I am aware that it’s no good but I need to admit that I sometimes indulge! The outcome of such indulgence is that the next blood sugar test will show a high reading. I love eating candies and French fries, but I try to avoid them as living with diabetes doesn’t allow me to have my favourite snacks. My aunt has taken notice of this and makes excellent almond or other healthy cookies, which are highly nutritious and tasty.

My dream is to become an aeronautical engineer.

My mother used to come to school every day to check my blood sugar level and give me insulin injections but for some time now, I have been managing it on my own. I take note of the blood sugar reading and inform my mother every day. At school, we have a nurse who takes care of medical emergencies and she is aware of my condition and knows that I must take special care of myself. My parents make sure I eat sensibly at home, but snacks and different kinds of food my friends offer me at lunchtime become a great challenge due to peer pressure at school.

Vivaan Thawani is a spirited boy who has been living with type 1 diabetes for nearly eight years. He was diagnosed with type 1 diabetes when he was four years and four months. Frequent urination was the first obvious symptom and subsequent preliminary tests revealed very serious diabetes. After a brief hospitalization, Vivaan’s parents recovered from the initial shock and became aware of their son’s diabetes management requirements at home as well as at school. Vivaan currently lives in Mumbai, India and will celebrate his twelfth birthday in October 2013. On a rainy day, Vivaan agreed to take some time off his busy school vacation to discuss a typical school day with type 1 diabetes.
'My Name is Rachel and I have lived with type 1 diabetes for 15 years. I was diagnosed with diabetes when I was just 21-months-old, which means my family and I had to learn to deal with many challenges at school from the very beginning.

My first memory of diabetes at school was when I was five and in kindergarten. It was late in the year and the weather had turned warm. My teacher told the class that because we had been so good that we earned extra playtime. I remember running around with my friends and playing and when we came back into the classroom I didn't feel right, but I couldn't explain my symptoms adequately. I told the teacher my feet felt like jelly with pins and needles, but she didn't understand how this was related to diabetes. She yelled at me, accused me of telling lies and told me to go sit in the corner.

That's all I remember because I became unconscious and my mom told me the rest. My blood sugar dropped so low that I passed out on the floor as if I was taking a nap. Fortunately, the school nurse walked by and rushed in yelling to my teacher to call 911. The kindergarten teacher wouldn't help, but the nurse picked me up and ran me straight to her office where my extra supplies were kept. She administered glucagon while she waited for my mom and the paramedics. I recovered fully from the hypoglycaemic episode, and was fine thanks to the nurse's quick action.

I remember going back to school the next day and the kids were afraid to be around me. My mother and I were not allowed time to explain to the class that it was diabetes that had caused the problem. After that year, my mom insisted that all school staff receive training from the American Diabetes Association (ADA) or a nurse educator from Joslin Diabetes Center. For the past seven years and even today, a professional visits my school every September to talk about diabetes to the entire school staff so what happened to me in kindergarten will never happen again to another person who attends my school and lives with diabetes.

‘Diabetes is just a part of me, not the whole of me.’

The second most memorable diabetes experience at school was in fourth grade when I remember feeling so excited for the first day of school that my nerves made my blood sugar drop. I went low really fast! My teacher, Mr. Clark, picked me up and ran me straight to the nurse where I drank juice until I was OK. When I got back to the classroom a half hour later Mr. Clark decided to introduce a new topic and asked the class to think about characteristics that make everyone unique. He told us that he was ‘good at sports’ but that he also lived with a chronic illness called Crohn’s disease. He explained to us that if he ate something that wasn’t on his diet he could get really sick. He then invited each of us to talk about ourselves. When it was my turn, I talked about my love for dance and music, and also informed my classmates that I lived with a condition called diabetes. I explained how my blood sugar had gone so low in the morning that I needed some juice to help elevate it to a safe level so I wouldn’t pass out. I also pointed out how no one was at risk of catching diabetes from me. From that moment forward, friends and classmates understood that diabetes is just a part of me, not the whole me.

I hope my experiences and how my family developed a strategy to educate the school will help others as they move forward in their diabetes journey.'
Diabetes doesn’t stop me

Eduardo da Silva is relatively new to type 1 diabetes, but he is already a Pro at managing the condition with total preparedness for his seventh grade class. Checking his blood sugar five times a day, especially before he plays football, is meaningful for Eduardo because he dreams of becoming a professional football player right in his home town of São Paulo, Brazil. In this feature, Eduardo takes a break from the field and talks about the discipline evident in his daily life – a necessary sacrifice in order for him to achieve his goals.

‘My name is Eduardo, and I am 12 years old. Two and a half years ago, I found out that I have type 1 diabetes. At first it was difficult to accept the changes. I joined the ADJ Diabetes Brasil and as time passed, I realized that other people also have diabetes and live well. I have two brothers, but no one else in my family has diabetes.

‘I always carry everything I need for diabetes with me.’

I lead a normal life. As with everyone who has diabetes, my blood sugar sometimes changes, but when the numbers get too high I make corrections. I also give myself insulin injections and test my blood glucose at least five times a day in order to know how my numbers look.

I am in seventh grade and my teachers and friends all know that I have diabetes. When I have a hypo (hypoglycaemic episode or low blood glucose), they help me. At one time there was another boy in my school with diabetes, but he no longer attends.

Every school day, I wake up at 5h30 am, tidy up my stuff, and do my blood glucose test before I eat breakfast. I leave home and wait for the bus to pick me up for the ride to school that is in Vila Guilherme. I am in school full-time from 7h00 in the morning to 4h10 in the afternoon, which is just over nine hours.

I always carry everything I need for diabetes with me like my insulin, glucose meter, test strips and I always make sure I have snacks. At school, we have a snack in the morning and one in the afternoon. Sometimes I get hungry and eat a muesli bar, which is no problem because I do carbohydrate counting. The school prepares lunch and the food is good. Usually we have rice, beans, salad, and meat. My favourite food is rice, beans, and chicken breast. Yum! If there is a party, my doctor says I can eat a thin slice of cake if I count the carbohydrate amount and take extra insulin.

‘Diabetes does not stop me from anything – my dream is to be a footballer.’

I always do my blood glucose tests before meals or snacks, but I also must do them before physical activity. When I am at school playing volleyball and basketball in physical education classes, I must check to make sure my blood glucose is OK. My mother always supports me and notices symptoms of hypoglycaemia (low blood glucose) and hyperglycaemia (high blood glucose). She always reminds me that I should never hide anything from her.

At home, in my spare time I like watching TV, and playing video games. I also like going to the movies and I love comedies. Another thing I like to do is read books, especially books about sports.

My dream is to be a footballer. I cheer for the team from São Paulo Futebol Clube and my idol is the goalkeeper Rogério Ceni. Pretty soon, I’ll start training the Portuguese Football Club.

Diabetes doesn’t stop me from anything.’
The Diabetes Voice Inbox

This new Diabetes Voice section will feature comments from our readers, sometimes on specific articles in previous Diabetes Voice issues, sometimes more general comments on how the magazine’s content is developing. The Editorial Team reserves the right to abbreviate submissions if necessary. Additional comments may be posted on the Diabetes Voice webpage www.idf.org/diabetesvoice. Readers who wish to contribute should send their comments to diabetesvoice@idf.org.

How low can you go? – The low-carb debate

In our June 2013 issue, Diabetes Voice presented the first diabetes debate focused on the validity of low carbohydrate nutrition for type 1 diabetes. We asked two certified diabetes educators to present their side – YES or NO – on whether or not a nutritional regimen based on low carbohydrate intake provides safe and more effective glycaemic control for healthy type 1 diabetes management.

We received the following response directed to Carolyn Robertson, who represented opposition to very low carbohydrate intake for the debate:

Glucose has been little explored in type 1 diabetes and the best paper is Kacerovsky (2011). In this paper she showed that endogenous glucose production (glucose coming from the liver rather than from the diet) was 42% higher in poorly controlled people with type 1 (HbA1c 8.5 ± 0.4%) than controls and 25% higher than those with well controlled diabetes (HbA1c 7 ± 0.3%) and the range between the lowest and the highest individual with diabetes was from 12 to 20 μmol/kg/min. This range is likely to be much lower than the day-to-day or meal-to-meal glucose range within an individual. Meal responses are much more variable with 10-20 fold differences between individuals in area under the glucose curves regardless of degree of diabetes control. We know many individuals struggle to predict the response to a standard meal, which can vary dramatically from day to day. In these individuals it is well worth a trial of lowering the carbohydrate content of the diet to see if control improves. If it doesn’t work after 3 months then a normal diet can be resumed. For a 70 kg person with type 1 diabetes the liver contributes a maximum of 15 g/h of glucose so it is little different to the effects of small 60 g carbohydrate meal over 4 h.

Peter Clifton is Professor of Nutrition at School of Pharmacy and Medical Sciences, Sansom Institute, University of South Australia.

Carolyn’s response is as follows:

Since there is limited data looking at the impact of gluconeogenesis in individuals with type 1 diabetes, we must rely on what is known. Restricting carbohydrates below what is needed for consumption by the brain causes the system to rely on gluconeogenesis to provide the fuel it requires. Since this process is neither continuous nor predictable, the resultant glucose output is likely to create challenges to the individual who needs to know how much insulin to take based on the ambient glucose regardless of whether the glucose comes from dietary sources or endogenously from liver’s output of glucose.

If the glucose output does not match the estimate, then the resultant glucose levels will be labile - less glucose output is likely to cause hypoglycaemia and more glucose output is likely to cause hyperglycaemia. At some point the production of glucose becomes constant but the minimal carbohydrate threshold is not really known - though I suspect it varies person to person. I agree that dosing for a diet high in carbohydrates especially if they are refined, or contain predominately simple sugars is a challenge and the risk of miscalculating is high. I prefer to recommend a reduced carbohydrate diet that contains 40% carbohydrate from low glycaemic, high fibre sources versus a diet with 50-60% or more carbohydrate.

Carolyn Robertson is a Clinical Nurse Specialist who is certified as a Diabetes Educator as well as board certified in Advanced Diabetes Management.

Reference
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