

Spotlight on an IDF Member: the Dutch Diabetes Association

Maarten Ploeg and Annemarie Bevers

Like many of its fellows, the Dutch Diabetes Association (DDA) is faced with a growing number of people with diabetes — currently nearly 1 million out of a total population of 16 million people. About 58,000 of these people with diabetes are members of the DDA. In order to support members' diabetes management, and attract new members, the DDA has developed several Internet-based applications to reach out directly to increasing numbers of people. In our 65-year history, we have evolved from an organization that secured insulin for people with diabetes into an organization with ties to the general public, politicians and policymakers, insurers and a range of other stakeholders.

Much effort is put into the prevention of type 2 diabetes in The Netherlands. The DDA participates in the National Action Programme, funded by the Ministry of Health. Since organization represents people with diabetes, these are our main focus. Our guiding principle is that people with diabetes should be able to take care of themselves at all times. That is entirely possible given the current status of health-care in our country. Insurance companies and healthcare providers are equipped and able to share responsibility with people affected by diabetes. Empowering people with diabetes to take up a central role in their own care is an important area of our work. Our next key goal is to gain access to confidential digital health records – without these becoming available to any other party. In this article, we will explain how.

Reaching out online

To start with, the DDA connects people with diabetes with one another through several websites linked to the main Association site (www.dvn.nl). There are websites for diverse target groups: children with diabetes up to the age of

12 years; teenagers and young adults (12 to 18 years); adults and parents – through a forum for sharing concerns and knowledge about diabetes issues. A DDA diabetes Wikipedia offers a range of diabetes information that has been assembled over the years.

The DDA e-shop ensures the wide availability of reasonably priced diabetes supplies.

To connect these and several other interesting DDA Internet initiatives, we created a personalized Internet portal, 'my diabetes online' (www.mijndiabetes.nl). Here, users can set up their own account and arrange diabetes information in an order that is relevant to their own situation – creating in this way a personalized 'diabetes dashboard'. The DDA has incorporated in the portal an online e-shop, where essential diabetes supplies can be purchased. Up and running since 2008, the role of the e-shop is to ensure the wide availability of diabetes supplies at reasonable prices.

Personal health information available on a personal level

Our mission, to support all people with diabetes in accessing good care and living a normal, healthy life with diabetes, underpins all of our decisions and activities. To this end, the personalized Internet portal will, in the long run, offer a range of personal diabetes information to individuals. Personal health records currently belong to healthcare providers; the DDA adheres to the belief that this type of information should belong to the person with diabetes. We encourage diabetes healthcare providers to make personal health status available online. Access to this information via the DDA portal will remain confidential and free of charge for all users.

Going out tonight? Check your dinner!

The DDA's most recent initiative is called 'Check your dinner', where people with diabetes (and people

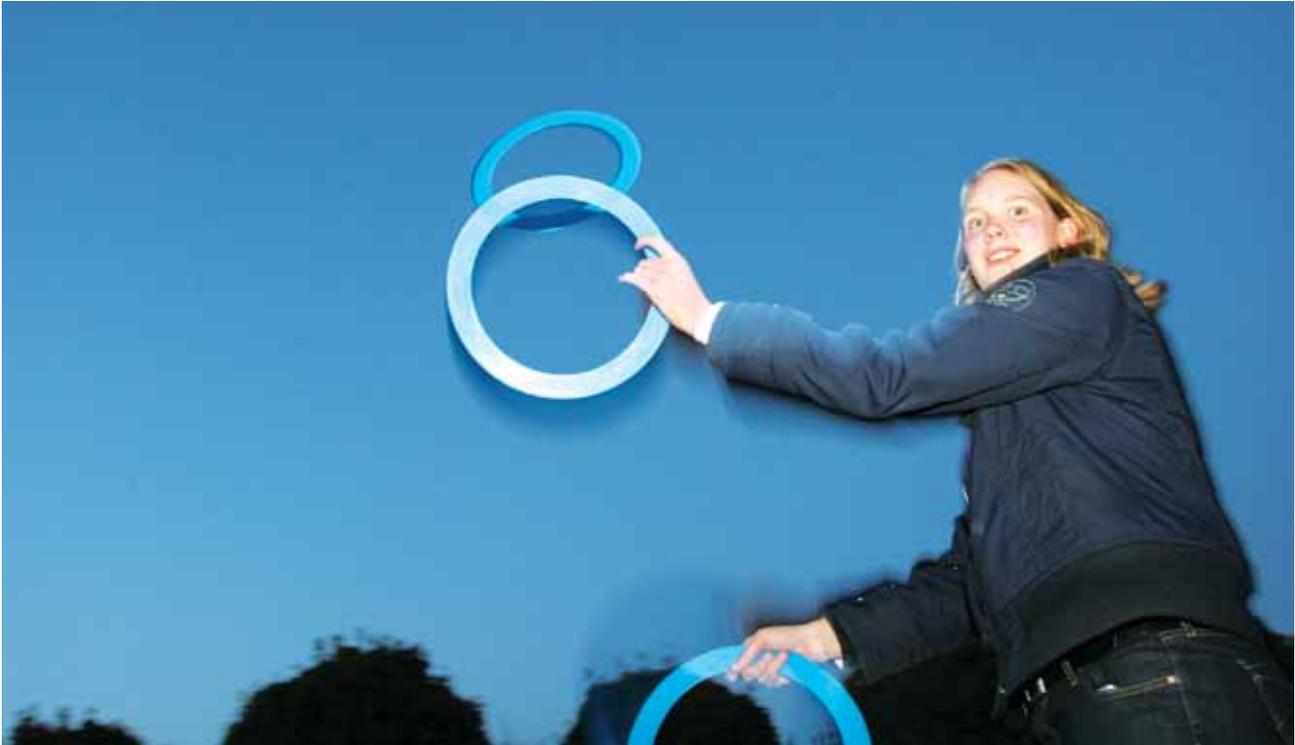
without diabetes) can calculate the carbohydrates and calories on offer in a restaurant's menu before choosing a place to eat. Under the scheme, restaurants make their menus available to the DDA's nutrition experts, who then calculate these values. This simplifies decisions regarding the number of units of insulin a person needs to take. Apart from the advantages for people with diabetes, 'Check your dinner' offers participating restaurants a new way of presenting themselves to the public – caring and conscientious and playing a part in improving public health.

DDA – totally web based?

We have seen a sharp rise in the use of the Internet in The Netherlands. It is essential for our organization to be active online and thus accessible to growing numbers of people. But of course, we also offer offline communication: a monthly magazine, Diabc; a 24-hour phone service for non-medical questions about living with diabetes; a nationwide network of volunteers organizing informative events and inviting people with diabetes and people without diabetes to work out together.

'Check your dinner' allows restaurants to play a part in improving public health.





The DDA has a track record of political advocacy on behalf of people with diabetes. We have managed to influence Dutch and European policymakers in a number of ways. The DDA set up the National Diabetes Federation (NDF) in 1995 in order to compile all current knowledge on the treatment of diabetes. Member organizations of the NDF represent healthcare providers as well as people with diabetes. The combined strength and united voice of these organizations under the NDF umbrella was responsible for launch of the National Action Programme.

Dutch Diabetes Care Standard

In 2007, the NDF published the Diabetes Care Standard for Dutch healthcare providers, which outlines the basic diabetes care that is necessary to stay healthy. In 2008, this document was adapted for people with diabetes and a checklist added, enabling individuals and their family to check whether they are receiving the full care package to which

they are entitled. A survey, Diabetes Care Monitor, was conducted in order to determine whether people with type 2 diabetes were aware of their personal care plan. This plan, co-written by the person with diabetes and his or her diabetes healthcare provider, forms the basis for personal diabetes care. It makes living with diabetes easier – for example, by timetabling all necessary check-ups. The survey results told us that a lot of work remains to be done so that people with diabetes can lead a life without many of the burdens of the disease.

Much remains to be done so that people with diabetes can live free from the burdens of the disease.

Keep on keeping on

The survey was repeated recently and this time also solicited the opinions of people with type 1 diabetes regarding

the care they receive. From the results of these nationwide consultations, it has become clear that incorporating a personal care plan into the personalized webpage is an urgent requirement. Indeed, the options for entering personal data by both the user and the healthcare provider need to be expanded in order to provide a comprehensive and effective personal plan. Patently, our efforts and expertise are still very much needed. We will continue working to advance our mission for as long as we are needed.

Maarten Ploeg and Annemarie Bevers

Maarten Ploeg is Director of the Dutch Diabetes Association.

Annemarie Bevers is a board member of Dutch Diabetes Association and IDF Europe.