It Takes a Brain, a Heart, Courage, and Support

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I am pleased to share here my journey as a diabetes educator and behavioral researcher at the University of Pittsburgh in Pennsylvania and the journey of the READY-Girls preconception counseling program for adolescents. I will focus on preconception counseling for teens, starting at puberty. I will address the importance of adopting a cultural and linguistic competence approach to health care and education and touch on the need to facilitate social support networks for teens with or at risk for developing diabetes. Additionally, I will emphasize the crucial role diabetes educators play in providing all types of support, including preconception counseling, for youth with diabetes.

Following the Yellow Brick Road

The title of this article, and of the address on which it is based, reflects a theme I selected to illustrate my key points: *The Wizard of Oz*. I hope to draw parallels between Dorothy Gale's journey with her friends in that classic film and the development of our programs, as well as larger efforts to care for people with diabetes. They are all linked by the power of support.

Dorothy's journey begins on a yellow brick road, along which she meets Scarecrow, who wanted a brain; Tin Man, who wanted a heart; and Lion, who wanted courage. Together, they became her support network, helping to guide her on her way to visit the wizard and ultimately ensure that she could return home to Kansas.

My own journey began at Boston Children's Hospital, and my support network included my mentors Jay Sosenko, Joe Wolfsdorf, and Stephanie Schwartz. I spent 4 years as a diabetes educator and clinical nurse specialist there, but it was only after I left to start a doctoral program that I became aware of preconception counseling and all of the opportunities I had missed with the teenage girls who were in my care to start counseling them and raising their awareness about how to ensure healthy pregnancies.

This new awareness led me to develop the READY-Girls program, whose inception began at the University of Michigan. While earning my doctorate in the School of Public Health there, I was a graduate student researcher and project director for Bill Herman and Nancy Janz, who were exploring the question: "What factors predict that women with diabetes will seek preconception counseling?" The answer they identified was that women were more likely to seek such counseling before pregnancy if their health care provider (HCP) had recommended doing so (1). We also found that preconception counseling was cost-effective (2). That is how preconception counseling became my journey in life—my own yellow brick road. My mission and passion was to develop a program for teens that would provide preconception counseling early and often.

At the same time, I was conducting my own study for my dissertation on the need for social support and social networks for teens with diabetes (3). I found that mothers and friends were the strongest members of teens' social networks and that emotional and informational support were among the strongest predictors of health outcomes. Teens who perceived having greater support had better outcomes. Marshall Becker, who was chairman of my doctoral committee, was one of the developers of the Health Belief Model, which became a core conceptual framework for our READY-Girls program. Other mentors on my dissertation committee—Barbara Anderson and Neil White—remained part of my own social network for life. Marika Kovacs, mentor for my post-doctoral fellowship in Pediatric Psychiatry, further

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supported my development as an independent behavioral researcher in youth with diabetes.

Building the READY-Girls Program

I combined the findings from both of these University of Michigan studies to develop READY-Girls, through which teens with diabetes would get the early preconception counseling they needed with help from support networks of mothers, HCPs, friends, and peers. The program was developed with some stark facts at the top of our minds.

- High blood glucose caused by diabetes can cause reproductive complications (4). Up to 9% of women with diabetes who have unplanned pregnancies have complications, which could include stillborn fetuses, miscarriages, preeclampsia, and infants with congenital anomalies (5).
- Up to two-thirds of women with diabetes have unplanned pregnancies (5).
- Sexual activity generally begins in adolescence; by the age of 19 years, 76% had had sex (6). In our studies, teens' first sexual experience took place at 15.6 years on average (7,8).
- Forty percent of teenaged girls with diabetes in our studies had had an episode of unprotected sex (7,8).
- Teens in our studies were initially unaware of preconception counseling or reproductive complications, they had had early and sometimes unsafe sexual experiences, and they were at high risk for an unplanned pregnancy (7–9).

The READY-Girls program was designed to help solve these problems, as we knew that reproductive complications can be reduced from 9 to 2% through the provision of preconception counseling to safely plan pregnancies and attain tight metabolic control prior to conception and throughout pregnancy (5). Deciding what age-group to target was easy. We knew from our research and experience that young adolescents starting at puberty (~13 years of age) need developmentally appropriate information with a sensitive, proactive, preventive approach before becoming sexually active to empower them to make informed choices regarding reproductive health. Since 2009, the American Diabetes Association has included in its annual *Standards of Medical Care in Diabetes* a recommendation stating that, "Starting at puberty, preconception counseling should be incorporated into routine diabetes care for all girls of childbearing potential" (10). I am proud that our research with the READY-Girls program provided the evidence base to support that recommendation (8,11).

So, what exactly is the READY-Girls program? Its name is an acronym for **R**eproductive Health **E**ducation and **A**wareness of **D**iabetes in **Y**outh for **Girls**. It is a theory- and evidence-based preconception counseling program that was originally offered as a CD-ROM (12) and later evolved into a DVD (13), video, and then online format, always with a book targeting teens with diabetes (Figure 1). The program incorporates facets of several theoretical models and guidelines, including the Expanded Health Belief Model (14), the STAR Decision Model (15,16), and the Cultural and Linguistic Competence Health Approach (17). From the Health Belief Model, we incorporated the understanding that knowledge and positive health beliefs are necessary to change health behavior, which in this case meant empowering girls to use effective family planning, seek preconception counseling, and feel confident in initiating discussions around such issues. We also incorporated the concept of social support, recognizing that such support has both main and buffering effects on health. We looked at Tardy's methods of measuring social support and defining social networks (18), and specifically at the different types of support: informational, emotional, appraisal, and instrumental. We also looked at different social network members, focusing specifically on family, friends, and health care professionals.

Diabetes Educators Are Wizards

Looking again at the different types of support, we can see that informational support is education and counseling, emotional support is listening, appraisal support is praise and encouragement, and instrumental support is tangible aid. Teens with diabetes need all four types of support for a successful journey toward improved health and well-being. In that regard, they are like the characters in *The Wizard of Oz*. Scarecrow needed a brain (informational support). Tin Man required a heart (emotional support). Lion needed courage (appraisal support). And Dorothy needed a way home (tangible support). The Wizard told them that they already had what they sought. All they needed was affirmation and tangible support in the form of tokens (a diploma for Scarecrow, a heart-shaped clock and testimonial for Tin Man, and a medal of valor for Lion), as well as a balloon ride home for Dorothy. And just like the Wonderful Wizard himself, diabetes educators provide all four types of support, help people living with diabetes recognize their own internal resources, and become a member of their support network.

READY-Girls: Content and Outcomes

Our READY-Girls program provides informational support. For teens with diabetes, it's about more than how to

FIGURE 1 Tailored versions of READY-Girls program materials.

prevent an unplanned pregnancy. It is also about knowing how to plan a safe pregnancy when one is wanted. Toward that end, we provide general information about diabetes and pregnancy and the risks of complications; we also talk about the importance of planning and preconception care for ensuring a healthy pregnancy, as well as about the crucial need to attain glucose control before conception. We also talk about how to prevent an unplanned pregnancy and provide family planning advice.

Through the years, we have examined the effects of participation in the READY-Girls program on intentions and behaviors for family planning and preconception care in teenaged girls with type 1 or type 2 diabetes and have looked at those effects over 6–12 months (7,8,19). We have found that knowledge is necessary to change behavior, but alone, it is not enough. Knowledge, health beliefs, and awareness of preconception counseling were all associated with positive health behaviors. Our program increased all of these requirements for behavior change—knowledge, beliefs, and awareness—as well as perceived support with reproductive health issues. We also found that READY-Girls was cost-effective. After participating in READY-Girls, individuals in the intervention groups were more knowledgeable about diabetes, pregnancy, and sexuality; perceived having more support; and perceived greater benefit from and fewer barriers to preconception care. They were also likely to be more consistent in their use of effective birth control, to seek out preconception care, and to initiate discussions with their HCP, as well as to have lower A1C values. Additionally, we found that providing boosters in the form of additional exposure to the program content was an important factor to ensure the intervention's long-term success.

We also did a 15-year follow-up study along with Dorothy Becker (20). This study involved women with diabetes who, as teens, had participated in one of three cohorts from previous READY-Girls randomized controlled trials (RCTs) at Children's Hospital of Pittsburgh, who were tracked in the diabetes registry and compared with women who had never registered in READY-Girls. We found that those who first received preconception counseling during adolescence had greater family planning vigilance. This meant they were older at sexual debut (18.5 vs. 15.4 years), more likely to have

used combination birth control methods, and more likely to discuss preconception care with their HCP. Thus, we confirmed that early instructional programs like READY-Girls can empower young women with diabetes to make well-informed reproductive health choices.

It is important to note that READY-Girls does not replace education and counseling from HCPs, but rather reinforces and supplements it. Mothers can also play a major role in ensuring that their daughters receive preconception counseling and reinforcing those messages. For these reasons, we also need to provide preconception care knowledge and skills to both HCPs and mothers. We offer continuing education programs for HCPs on our University of Pittsburgh School of Nursing website (www.nursing.pitt.edu), and READY-Girls materials specially adapted for the ADA (11) are available free of charge on its website (www.diabetes.org/ReadyGirls).

Modifications for Cultural and Linguistic Diversity

Thirty years ago, when READY-Girls was created, >90% of teens with diabetes had type 1 diabetes and were Caucasian. Since then, the program has been modified as needed for diverse populations such as African American, Latina, and American Indian teens, as well as those with type 2 diabetes. To do this, we have embraced the culturally and linguistically competent health promotion principles laid out by Bronheim and Sockalingam (17). These are crucial principles for all health care and education endeavors and include:

- Understand and respect the values, beliefs, and practices of the intended audience.
- Consider the social, environmental, and political context.
- Recognize the family and community as primary systems of support and intervention.
- Ensure that the effort exists in concert with natural and informal health care support systems.
- Ensure the meaningful involvement of community members and key stakeholders.

These principles, and especially the ones specifically addressing the importance of support from family, community, and HCPs, were baked into our programs. Modifications always started by conducting focus groups with HCPs who care for teens in each targeted group (21–23). We also used markups as a methodology, asking members of our target audience to mark existing READY-Girls materials with comments on what they liked, what they did not like, and what they found particularly relevant to their culture. These exercises yielded many insights. For example, our original READY-Girls CD-ROM and book, primarily for a Caucasian audience with type 1 diabetes, was quite wordy and featured small, rather technical illustrations. Later, we tailored the program for more diverse groups, including African American teens and people with type 2 diabetes in collaboration with Dr. Julie Downs; Spanish-speaking adolescents and their mothers, with assistance from Ethel Codner, Franco Giraudo, Ellen Olshansky, and Amy Case; as well as for a younger age-group (changing from the original 16–20 to 12–20 years of age), which necessitated a new chapter on puberty. As shown in Figure 2, the tailored materials became less technical and, for distribution through the ADA, they were given a fresh look. In addition, Drs. Codner and Giraudo collaborated with us and the Juvenile Diabetes Foundation of Chile to adapt our materials for use by Chilean teens with diabetes.

Shifting the Focus to Gestational Diabetes

More recently, in collaboration with Kelly Moore, we have undertaken a large-scale adaptation of READY-Girls to address high rates of gestational diabetes mellitus (GDM) in the American Indian and Alaska Native (AI/AN) community. AI/AN women are disproportionately affected by adolescent obesity, adolescent pregnancy, and GDM, all with prevalence rates nearly twice those found in the general U.S. population (24,25). GDM in turn increases the risk of obesity and diabetes in the offspring of these women, creating a vicious cycle. Thus, the need for early intervention to prevent GDM among AI/AN girls and young women is compelling.

We adapted READY-Girls for Native American girls to reduce their risk for eventually developing GDM. We call this program Stopping Gestational Diabetes Mellitus (Stopping GDM), and we have evaluated its effectiveness in five diverse clinical and community settings across Indian Country.

We started with focus groups that included AI/AN teen girls, mothers/caregivers, and women in their communities with previous GDM or diabetes, as well as tribal leaders and HCPs of AI/AN women (26–28). These participants asked for depictions of generations of Native women and of actual people—not actresses or models. They wanted to hear real stories and see traditional physical activity and sports, as well as traditional foods. They asked for program materials to be conservatively presented with a respectful approach and no frontal nudity in illustrations. They also requested the use of traditional colors and patterns, such as symbols representing the four directions and an emphasis on balancing mind, body, and spirit. As in the past, these materials also featured pictures of mothers with daughters.

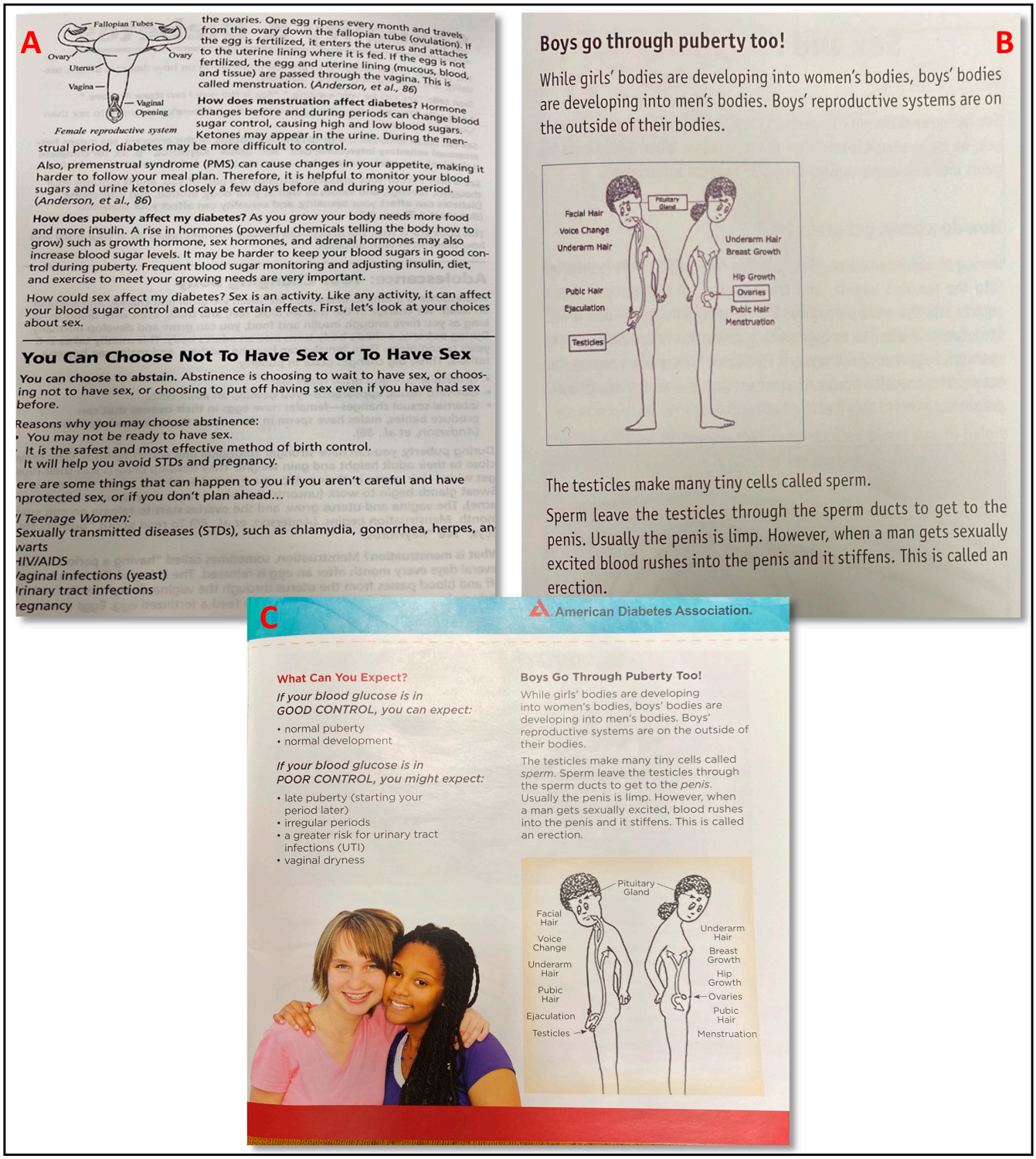

FIGURE 2 Sample content from the original READY-Girls materials (*A*); a later, tailored version (*B*); and a version made available at no charge from the ADA (*C*).

In our RCT for Stopping GDM, online education sessions for each mother/daughter dyad included a video at baseline, as well as an e-book at 3 and 6 months, as a booster. Both the intervention and control groups received March of Dimes pamphlets at initial visits, and the control group received the Stopping GDM video and booklet at their

final visit at 9 months. The RCT also included an online pre- and post-intervention survey, as well as a cultural toolbox focusing on tribal customs and concepts regarding reproductive health, coming-of-age ceremonies, local traditions, community resources, and other resources available outside of the local community or online.

In our pilot study (28), changes in pre- and post-intervention survey scores showed significant trends of improvement in the hypothesized directions: daughters improved in knowledge and self-efficacy, mothers improved in knowledge and intention to initiate discussion, and mothers' knowledge was associated with daughters' risk perception.

The Stopping GDM program is freely accessible on our website (www.stoppinggdm.com).

Future Directions

We are now planning to expand Stopping GDM to reach not only American Indian communities, but also Native Hawaiians and Alaska Natives. In addition, under the direction of Andrea Fischl and in collaboration with Ingrid Libman, our team is developing a READY-Guys program. Boys and young men also face reproductive health complications, and getting their glucose levels into the target range can decrease these risks. They, too, need preconception counseling. Evidence of this came from one of our surveys, in which we asked 15 male youth with diabetes to identify what they believed to be the most concerning complication of diabetes. Not one selected reproductive health.

Support Leads to Empowerment

One of the most important takeaways from our experience with READY-Girls is that support leads to empowerment. Returning to *The Wizard of Oz*, remember that Dorothy's confidence grew through her journey, with the help of her support network, and that she eventually realized she had what she needed to reach her goal. To paraphrase Glenda the Good Witch, Dorothy had always had the power; she just had to learn it for herself.

Following are some of the other key points I have tried to emphasize:

- It takes a brain, a heart, and courage to manage diabetes!
- Youth with or at risk for developing diabetes need all types of social support.
- Lucky for all of us, diabetes educators provide all types of social support.
- Preconception counseling for youth with diabetes should start at puberty, with information boosters at every clinic visit; address preconception counseling early and often.
- Both girls and boys need developmentally appropriate reproductive health and preconception counseling.
- Recognize the value of social networks and respect the culture of your target audience.

My final message is that support leads to empowerment and that, as Dorothy learned from her support network, the power we need lies within us.

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DUALITY OF INTEREST

No potential conflicts of interest relevant to this article were reported.

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