



In this issue of the T1D Exchange Participant Newsletter:

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Thank you for making a global impact!

Each day, we work with investigators and researchers from nonprofits and industry to better understand the challenges of living with T1D. Your continued participation in the T1D Exchange Clinic Registry and other T1D Exchange programs makes a major impact for all of us working together to improve care and accelerate new discoveries. On May 6, we hosted our second annual meeting with more than 100 thought leaders from the T1D research community—our partners from companies, JDRF, ADA, and other funders were in attendance. We highlighted important findings, derived from the data you shared with us in the Registry and on Glu, and ensured your voice was heard. We also introduced the Living Biobank, a new resource developed to improve research participation. Our commitment to you is better care and faster solutions—none of this is possible without your continued dedication and commitment—thank you!

Dana Ball  
*Executive Director and Co-Founder, T1D Exchange  
CEO, Unitio, Inc.*

## Update from the Living Biobank

Thank you to all of you who have enrolled in the T1D Exchange Living Biobank! Some of you have already been called upon to provide a blood sample for the Living Biobank, while others may be contacted regarding donating blood in the near future. The T1D Exchange Biobank has already started to distribute samples stored in the Biobank to scientists studying T1D and its complications. One investigator using Biobank samples describes his work as follows:

*"We are trying to develop a non-invasive method to detect pancreatic beta cell death, to address a major challenge in type 1 diabetes research. The method requires the assessment of blood samples from a large number of well characterized type 1 diabetic patients. We did not have access to such a resource until we were referred to the T1D Exchange Biobank, from which we were able to obtain such samples after a simple application procedure.*

*The samples are being used to develop and optimize a new diagnostic assay for type 1 diabetes, which in principle may be used for early detection of the disease and for monitoring progression and the response to drugs.*

*The biobank not only saved time and effort, it provided us with a resource that we could not obtain otherwise."*

### DID YOU KNOW?

Participants in the Living Biobank agree to be contacted for scheduling a blood draw in response to requests from approved investigators studying T1D and its complications.

If you have T1D and aren't already enrolled the Living Biobank, please consider participating! Call 1-206-342-6942 (toll-free 1-877-280-5345) to get involved.

# T1D Exchange Clinic Network

## Upcoming Studies

- **Eating Patterns and Food Intake of Persons with Type 1 Diabetes:** The study will evaluate the association of eating patterns and food intake with glycemic control measured by HbA1c. Participants will be asked to complete two interviews via phone which will include questions about nutrition and eating habits.
- **Pediatric to Adult Health Care Transition Study:** This study will survey individuals 18 to 29 years old regarding their experience in receiving health care as an adolescent and as a young adult.
- **Racial Differences in HbA1c Levels:** This study will compare the relationship between glucose levels measured by continuous glucose monitoring and HbA1c levels in whites and African-Americans to see if there is any difference.

## Current Studies

- **The Clinic Registry:** Currently there are about 26,370 participants enrolled with at least one year of information collected on almost 22,000 participants
- **The Residual C-peptide Study:** Enrollment of 965 participants was completed in March 2013; 278 had detectable c-peptide levels indicating that the pancreas is still producing some insulin. These individuals are continuing to have c-peptide levels measured every 1-2 years.
- **Intranasal Glucagon for Treatment of Hypoglycemia:** The adult and pediatric studies have completed enrollment of 77 adults and 41 children. The studies will be completed in the next several months.
- **Metformin for Overweight Adolescents with Insulin Resistance:** This randomized trial completed enrollment of 140 participants at 27 clinic network sites in February. Follow-up is ongoing.

## Completed Studies

- **Insulin Use and Diabetes Devices Survey:** Almost 4,000 individuals completed this survey which will provide valuable information on diabetes management. Analysis Review of the study data is currently in progress.
- **Factors Associated with Severe Hypoglycemia in Older Adults:** The study completed enrollment of 201 participants in April 2014. Analysis of the study data is currently in progress.

*For more information about these studies, please go to the T1D Exchange website,*

[www.T1DExchange.org](http://www.T1DExchange.org)



During the first half of 2014 the following six T1D Exchange abstracts were presented at national and international diabetes meetings.

### Advanced Technologies and Treatments for Diabetes

- Twice daily versus once daily basal insulin does not result in better glycemic outcomes among MDI patients with T1D

### Pediatric Academic Societies and Asian Society for Pediatric Research

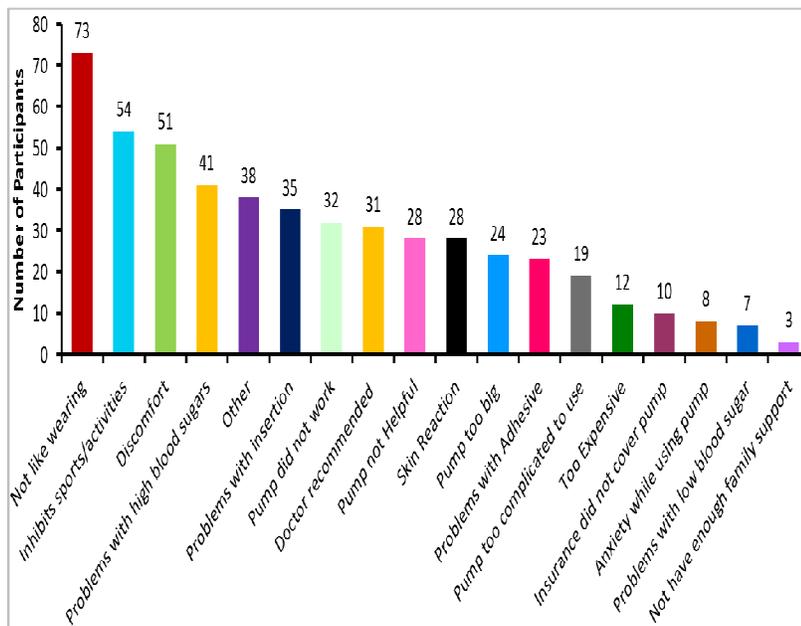
- Celiac disease and type 1 diabetes: Growth, weight gain, and family concordance in the T1D Exchange

### American Diabetes Association

- Better glycemic control but extended newborn ICU needs among pregnant women with type 1 diabetes in the T1D Exchange
- The obesity epidemic and its consequences in youth with type 1 diabetes (T1D) in the US T1D Exchange (T1DX) and German/Austrian DPV registries
- Twins concordant for type 1 diabetes in the T1D Exchange
- A web-based study of the relationship of insulin pump infusion set durations and fasting blood glucose (FBG) level in type 1 diabetes (T1D)

# Insulin Pump Discontinuation in the T1D Exchange Clinic Registry

- Although most individuals who start using an insulin pump like it and continue to use it, some don't. We found that during one year, 4% of T1D Exchange participants stopped using a pump
- Pump discontinuation was more likely in: adolescents, those with lower annual household income, those with shorter diabetes duration, and those who do not check their blood sugar as often.
- There were many different reasons given for why the pump was discontinued but the most common reason for pump discontinuation was dislike for wearing the pump. Other reasons are shown in the graph.



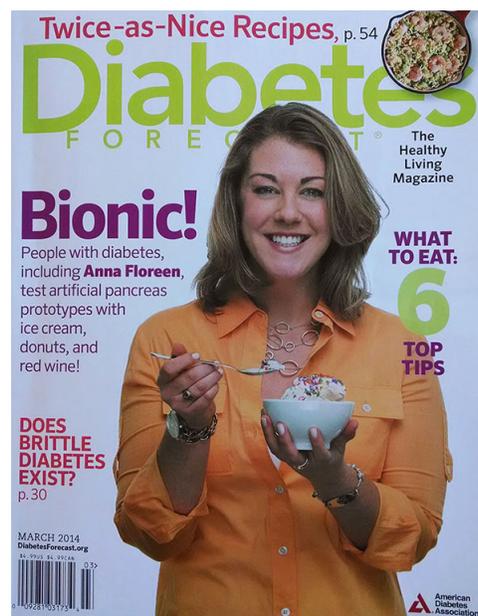
## Glu: T1D Research in Action!

Have you checked out Glu recently? Our online community has grown to more than 9,200 people living with type 1 diabetes, their caregivers, and supporters.

Glu is growing every day and is quickly becoming a powerful tool through which to conduct web-based research. We're proud to announce that two abstracts, "Exercise Patterns in Type 1 Diabetes: A Web-based Survey" and "The Relationship of Infusion Set Duration and Levels of Glycemia Study," were accepted for the American Diabetes Association's 74<sup>th</sup> Scientific Sessions.

On Glu, we conducted surveys on CGM use and are collecting feedback from the T1D community about technology and quality of life to share with experts at our annual meeting in May. Our community outreach manager, Anna Floreen, was featured in the March issue of *Diabetes Forecast* to discuss her experience with the Beacon Hill Study for the bionic pancreas.

Glu launched a highly successful awareness campaign about Insulin pump technology featured in *Diabetes Forecast* through their "Insulin Pump Bracket Challenge," in which Glu members were invited to vote for their favorite. The winner was Tandem DiabetesCare t:slim.



Feel free to contact the Institutional Review Board (IRB) office at [irb@jaeb.org](mailto:irb@jaeb.org) or the Human Research Protection Program (HRPP) office at [hrpp@jaeb.org](mailto:hrpp@jaeb.org) with any questions, concerns, or suggestions.



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