What We’ll Discuss

- The T1D Exchange Story
- The Science of It All: Research Happenings
- Patient-Driven Outcomes through Glu
- What’s in It for the Educator?
- Come visit us at booth number 131!

Who We Are

T1D Exchange is driving better, faster research to improve care and speed development of new therapies for people and families living with type 1 diabetes.

(better) More informed research from the very start, because our research starts and ends with the patient community.

(faster) Researchers have seamless access to resources they need to conduct clinical studies.

What We Built

CLINICAL PROGRAM

- 74 CLINIC SITES FOLLOWING 100,000 PATIENTS
- 27,126 CLINIC REGISTRY PARTICIPANTS
- 15,785 PARTICIPANTS ON GLU
- 2,100 PARTICIPANTS WILLING TO PROVIDE SAMPLES ON DEMAND

SCIENCE PROGRAM

- BIOSAMPLES FROM 2000 UNIQUE T1D PATIENTS
- 2,100 PARTICIPANTS WILLING TO PROVIDE SAMPLES ON DEMAND

Why It Matters

The only single-access model in type 1 diabetes in the United States that is dramatically improving the speed and success of clinical studies.
Glucagon
Proven to cause an excess of anxiety, worry, and fear

**KEEP CALM AND DON'T GO LOW!**

**Clinical Centers**

- Types of Patients:
  - Adult: 16%
  - Pediatric: 36%
  - Both: 23%

- Setting:
  - Institution: 45%
  - Community: 55%

75 clinics

**Our Clinical Approach**

- Adult: 59
- Pediatric: 15
- Both: 1

**Institution**

- Community
- Managed Care Setting

75 clinics

**Age in Years**

- <6: 718
- 6-13: 3219
- 13-18: 4935
- 18-26: 2751
- 26-50: 2669
- 50-65: 1645
- >65: 834

**Insulin Pump Use is Increasing**

- Enrolled 9/1/2010 - 8/1/2012
- Current 1/1/2015 - 12/31/2015

- Overall
- <5
- 6-<13
- 13-<18
- 18-<26
- 26-<50
- 50-<65
- >65

- 57%
- 61%
- 63%
- 54%
- 59%
- 60%
- 66%

- 54%
- 59%
- 60%
- 63%
- 64%
- 68%
- 63%
CGM Usage is Increasing but Still Low

Frequency of Diabetic Ketoacidosis* According to Age

CGM Device Type: Shift Towards Dexcom

Registry Recruitment Update (4/18/2016)

ADA HbA1c Targets Not Met by Most

Clinic Network: Completed Studies

- Metformin RCT
- Severe Hypoglycemia in Older Adults
- Intranasal Glucagon Study (adult)
- Intranasal Glucagon Study (pediatric)
- Health Care Transition Experience & Glycemic Control in Young Adults with T1D
- Celiac Disease
- Pump Infusion Set Duration
- Sleep Survey
- Metformin Clamp
- Racial Differences
T1D Exchange: Evidence

T1D Exchange Clinic Registry data demonstrates that there is much work to do as certain outcomes have worsened across metrics in all age groups over time.

- **HbA1C**: 8.7% to 9% in 13-17 y.o. and 8.4% to 8.7% in 18-25 y.o.
- **Targets**: Reaching age-specific target goals worsened in < 17 y.o. (23%-20%) and remained the same in 18-65 y.o. (31%)
- **Seizures**: Regardless of HbA1C levels, 6-9% of patients experienced one or more seizures or loss of consciousness events in a three-month period
- **DKA**: As HbA1C rises above 8%, the frequency of one or more DKA events in a three-month period rises from 4% to as high as 26%
- **Death**: 31 deaths reported in < 30 y.o. cohort. (3 hypoglycemia, 4 hyperglycemia, 2 from drug/alcohol and 2 suicides)
- **Obesity**: Dramatic increase from 30-46% in < 6 y.o. (comparing 9/2010-8/2012 vs 4/14-4/15) and incidence as high as 69% in the 26 to > 50 y.o.
- **Hypoglycemia**: Almost half of the 516 respondents reported losing consciousness from hypoglycemia

Clinic Network: Current Studies

**Strategies to Enhance New CGM Use in Early Childhood (SENCE)**
Summary: RCT to determine if CGM + structured curriculum improves glycemic control in young children less than 8 years old

**Diabetes Health Related Quality of Life (HRQOL)**
Summary: Validate suite of measures of diabetes HRQOL for individuals with T1D and their family members (parents and partners) across the lifespan, developed during Phase I of this project

Clinic Network: Upcoming Studies

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Clinic Network: Upcoming Questionnaires

**Substance Use in Patients with Diabetes**
Summary: Evaluate prevalence and correlates of alcohol and other substance use disorders in patients with T1D

**Diabetes Healthcare Professionals Registry Questionnaire**
Summary: Create a registry for T1D healthcare providers at T1D Exchange Centers/Clinics to serve as a platform to facilitate surveys of HCPs in order to measure and analyze clinical, educational and mental health practices, and resource used in T1D care.

**Pathways to Disordered eating in Adolescents and Young Adults with T1D**
Summary: Test an adapted risk model of disordered eating behaviors including physiological factors, diabetes regimen factors and psychological factors in a sample of adolescent and young adults with T1D.

**Fracture Questionnaire**
Summary: Determine the prevalence, sites, and age of occurrence of fracture in persons in the T1D Exchange.

QI Program: Why It Is Needed

We need actionable measures that help identify when patients need help managing and controlling their diabetes and what determining which interventions are effective for use by care teams and patients.

- **HbA1C**: is insufficient (current gold standard)
- **Outcomes Collaboration with JDRF**

QI Program: Goals

T1D Exchange seeks to transform from a comprehensive research network to a Learning Health System (LHS) in which healthcare, continuous improvement of healthcare, technological innovation, and research are all purposefully integrated to improve the care of patients and families with T1D.

- Create an enduring QI collaborative network that is fully integrated to support an Enhanced T1D research network
- Develop a knowledge-sharing Commons
- Build upon existing Registry success to support a LHS and deploy at care centers in the collaborative QI and learning network
QI Program: Health Policy Collaboration

T1D Exchange is partnering with JDRF and the Helmsley Charitable Trust on a Health Policy Initiative to improve health outcomes and access to T1D therapies & technologies.

Focused On
- Unmet Needs
- Healthcare Utilization
- Health Outcomes

Seeking To Understand
- Barriers to Therapies and Technologies
- Barriers faced by providers in prescribing

Establishing
- A program to evaluate and define measures other than A1c improvements in T1D clinical outcomes

T1D Exchange Biobank: Characterization

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<tr>
<th>Gender</th>
<th>#</th>
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<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>#</th>
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<tr>
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<td>85.10</td>
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<tr>
<td>Black Non-Hispanic</td>
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<tr>
<td>Missing</td>
<td>11</td>
<td>0.60</td>
</tr>
</tbody>
</table>

Descriptive statistics
- Mean (±SD) Range
  - Age at diagnosis: 17.80 (±13.43) 0-66
  - T1D duration: 17.80 (±15.73) 0-79
  - HbA1c (%): 7.94 (±1.47) 4.8-15.1

* 1,997 participants with biobank samples and in Clinic Registry

Science Program

Living Biobank: Why It Is Needed

- Provides direct access to a T1D population
- Provides detailed health information
- Pre-consented to specimen "on demand" specimen collection
- Creates a cost-effective biobank for complex studies
- Requiring serial sample collections
- Participants with special characteristics
  - Long disease duration
  - Presentation of comorbid diseases

Our Patient-Centered Program: MyGlu.org
Anna Floreen, MSW

We are a type 1 diabetes community who is accelerating promising research by seeking answers, sharing wisdom and offering support.

16,608 community users
307,161 questions answered

Join Now
Participants: 17,901 diagnosed with T1D: 9,736

101,725 discussions 3,979 parents/guardians

Why GLU? We provide answers to important questions

Why is there a need because the isolation is there...

What motivates you to stay engaged in the T1 community?

Top 5 reasons to stay engaged

1. Emotional support
2. Learning (tips, new technology)
3. Getting help & advice
4. Being able to help other people
5. I don’t know anyone with T1D offline

38% of people report joining online communities to engage with the T1 community.

N=951

Get support from people who get it

Learn and share your knowledge!

Access articles, the latest news, and a wealth of T1D wisdom.

“My daughter is just finishing 3rd grade and is the only child at school with T1D. It’s a learning process for them and us as we just hit our 1 year dx. I feel there is so much to learn and hope she can connect soon to others so she doesn’t feel so alone.”
Glu Research: What Can Glu Do?

On average, how many times per day do you check your blood glucose using a blood glucose meter?

Which devices do you use?

- No Devices (20%)
- Pump Only (28%)
- CGM Only (5%)
- Pump & CGM (47%)

The Research Process Starts with Us!

- Question of the day
- Comments, Statuses & Articles
- Survey Development
- IRB Approval
- Participation & Analysis
- Published Results

T1D Exchange: Building the Future

- Innovative Real-World Patient Data Model
- Robust Pipeline of Research Opportunities
  - Driving improved outcomes
  - Optimize healthcare quality & delivery
- Builds Best-in-Class Partnerships That Allow Us To....
  - Most effectively meet research needs
  - Maintain highest quality and efficiency
  - Leverage the power of our resources

Around 70% of Glu community members reported rarely or never carrying a glucagon rescue kit.

How frequently do you carry glucagon with you? (n=275)

- Always: 50
- Sometimes: 36
- Rarely: 60
- Never: 129

"The glucagon never leaves our cabinet."
"It is too expensive and has such a short shelf life...."
"Who would know how to use it, anyway?"

"I get a new prescription for glucagon every year...fill it and in over 20 years have never had to use it."
"My hubby has only ever had to inject me twice, but has found it so distressing we no longer hold a kit at home. We are a 5 minute drive from the hospital...."
"Yes, we always have a current glucagon on hand, but don't often carry it with us."
"Never had to use one, so I'm probably not going to refill it...if I can save $ with one less outlay I will do it."
"My husband has used the kit 3 times in the 30 years we have been together...it is funny that in the 40 years I have had 'D' that damned kit has not changed at all."
Partnering with Industry to Drive Faster Innovations: Intranasal Glucagon

1: Glu Patient-Driven Data
2: Developed series of questions on Glu to better understand this need
3: Needle-free rescue drug for lows
4: Designed/Execute Clinical Trials
5: Data published (ADA, 2015)
6: Product on path to FDA

In the last year, how many times have you seen a Diabetes Educator?

- I have never seen a Diabetes Educator: 5%
- None: 40%
- 1 times: 15%
- 2 times: 14%
- 3 times: 23%
- 4 times: 5%
- # OF RESPONSES: N=513

What do you feel is a Certified Diabetes Educator’s greatest value to the patient?

- Sharing knowledge: [Graph]
- Providing emotional support: [Graph]
- Giving suggestions and advice, troubleshooting: [Graph]
- Listening to my concerns: [Graph]
- Giving me more time than my doctor can: [Graph]

Driving Patient-Centric Research: DKA & Misdiagnosis

Were you in DKA when you were diagnosed with type 1 diabetes?

- Yes: 25%
- No: 75%
- Not Sure: 0%

What can we learn?

- Time: Time to talk, Time to listen, Time to analyze, Time to talk about new ideas, Time.
- It depends on the CDE. A great one can give you most of the information you need, but sometimes they feel like we are doing a good job, something that is hard to gauge on your own.

Listening…and responding

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Listening…and responding
Growing a more engaged population

Glu App

Smartphone first and smartphone dependent includes:
- Millennials & younger adults
- Those with low household incomes and levels of educational attainment
- Non-whites (12% of African Americans and 13% of Latinos are smartphone-dependent, compared with 4% of whites).

DiabeteSpeaks

Glu is a two-way street: how can you help?
- Join the conversation online
- Be present!
- Submit your topics of interest as questions of the day!
- We want to hear from you.

How Can You Help Us: Join our Community (collaborate with us, suggest research)

1. Complete Your Profile
2. Answer Question of the Day
3. Participate – In surveys
   - Add comments & statuses
   - On social media
   - At events and meetings!
Questions and Comments
Join at www.myglu.org