

Every 1 Welcome:

Using language
and story
to shift
perceptions
around the
type 1 diabetes
community

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*To Grandad,
always loved and always remembered.*

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Abstract

TYPE 1 DIABETES (T1D) is a chronic autoimmune disease that requires extensive self-management. Due to the daily demands of T1D, young adult and adult type 1 diabetics often lose momentum when managing their disease. Through exploratory research, it became apparent that a type 1 diabetic who is highly engaged in the T1D community is motivated, inspired and empowered by what the community has to offer. This individual is more positively and actively in control of his or her physical and mental health, contributing to an increased resilience towards “diabetes burnout.” However, despite the incredible benefits offered by the T1D community, there is an overall lack of participation. A gap exists between what the perception of the community is, and what it actually can provide for a type 1 diabetic. This thesis aims to transform the T1D community into something more familiar and reassuring, in order to appeal to those individuals who currently disregard the community as a resource. Through this process, the intention is to encourage these individuals to engage in the community and indirectly defeat burnout.

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Prologue: T1D Inertia

TYPE 1 DIABETES (T1D), formerly known as “insulin-dependent diabetes” or “juvenile diabetes,” is a chronic autoimmune disease that requires extensive self-management (“Type 1 diabetes,” 2014). T1D occurs when the insulin-producing islet cells of the pancreas are destroyed by the body’s immune system. Consequently, those living with T1D rely on an external source of insulin for life. T1D is often confused with type 2 diabetes, as both diseases involve inadequate insulin production (“Differences Between,” n.d.).* It is important to note that this project focuses specifically on T1D.

An individual’s successful T1D management is dependent on precise control of his or her blood sugar levels. These glycemic levels are largely balanced through insulin intake, carbohydrate consumption and physical activity. Other factors that impact blood sugar levels include stress, illness and changing hormone levels, which are very difficult to manage due to their unpredictability.

Author and creative director Chuck Eichten (2011) describes the day-to-day management of T1D as exceedingly onerous: “Balance every minute iota of your life, every waking and sleeping movement, every morsel you eat and step you take, with insulin. Do it precisely and do it right now” (p. 26). As a type 1 diabetic, these words resonate with me. I continually endure the physical symptoms of blood sugar fluctuations, while coping with feelings of embarrassment, fear and anxiety that are tied to these

* Type 1 diabetes is when no or very little insulin is released into the body. Type 2 diabetes is when the body cannot properly use the insulin that is released or does not make enough insulin (“Differences Between,” n.d.). These are two distinct conditions and should not be grouped together under the umbrella term “diabetes.”



FIG. 1 A gift from my family in celebration of my first “dia-anniversary”

oscillations. It is not surprising that by the start of my master’s degree, I had developed a negative relationship with my disease. Having lived with T1D for over fifteen years, I was growing increasingly bored, tired and resentful of the daily management requirements.

This was not always the case; many of my earliest memories of having T1D are very positive. At the onset of my diagnosis, my family, friends, teachers and coaches offered a tremendous amount of support. My parents and siblings in particular were very involved in my T1D. They participated in my healthcare and celebrated my diagnosis anniversary each year (FIG. 1). I looked forward to my monthly appointments with my endocrinology team at the vibrant and cheerful clinic at The Hospital for Sick Children in Toronto. Outside of the hospital setting, I participated in numerous T1D related programs and activities. I was fortunate to be able to attend a Canadian Diabetes Association summer D-Camp along with other type 1 diabetic

children. As a junior spokesperson for the Juvenile Diabetes Research Foundation, I had several exciting experiences that included public speaking opportunities, travel and celebrity run-ins.

As a child, these experiences helped me feel more engaged in my T1D. Over time, as I learned to manage my diabetes more independently, my level of engagement decreased. Many of my closest family members and friends seemingly forgot about my T1D; it became invisible to them. While I continued to visit my adult diabetes clinic regularly, I felt uninspired and alone. At the start of my master's degree, my overall lack of engagement, combined with my negative feelings towards my T1D, meant that I was rapidly losing momentum.

Introduction

DUE TO THE daily demands of T1D, young adult and adult type 1 diabetics often lose momentum when managing their disease. This thesis provides an opportunity to help these individuals rebuild and sustain momentum over a lifetime.

During my four years of undergraduate interior design study at Ryerson University, I had become increasingly aware of, and interested in, the profound impact of design on all aspects of daily living. As a first-year undergraduate student, I remember watching the documentary *Objectified* and hearing the words of Paola Antonelli (2009): “I want designers to be the culture generators... they should become fundamental bricks in any kind of policymaking effort.” Inspired by Antonelli’s aspirations, my role as both a designer and an advocate aims to facilitate a shift in perspective around T1D health and wellbeing.

Exploratory Interviews

AT THE ONSET of my thesis, I decided to engage in a series of exploratory, semi-structured interviews with twelve other type 1 diabetics between the ages of fifteen and forty-five. I wanted to challenge my assumptions and preconceived notions about T1D. I was also curious to discover how other young adult and adult type 1 diabetics were coping emotionally with the rigours of T1D. In an attempt to better understand the lived experiences of others, I began to seek out dialogue with type 1 diabetics. Paradoxically, I felt it essential to distance myself from this aspect of my research. I chose to have the interviews conducted and recorded in Toronto by my partner Adam Veroni, while I remained in Vancouver.

The resulting twelve audio recordings presented a series of enlightening conversations, akin to a podcast sequence on T1D. Prior to this, I had no contact with other type 1 diabetics in my adult life. The stories shared by the interviewees moved and inspired me and I was drawn to listen to the recordings multiple times. I was surprised by the emotional connection I felt towards this group.

When asked to discuss the positive aspects of living with T1D, one interviewee responded by saying:

The sense of community. It's pretty supportive, which is awesome. You can meet with a bunch of [type 1 diabetics] and you can just say, "my blood sugar is so high" and everybody knows what that means. Same with the lows, everyone knows that we just need to stop for a few minutes, whereas sometimes my other friends just don't get that. (Anonymous, personal communication, December 10, 2014)

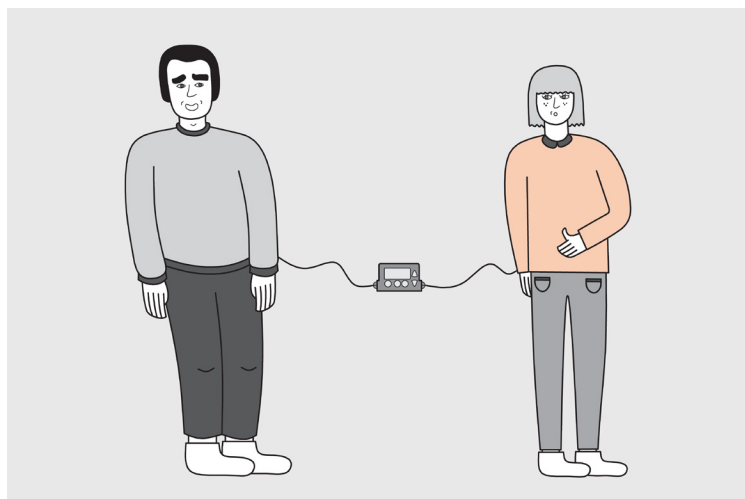


FIG. 2 The “Automatic Bond”

Three other interviewees alluded to the significance of community as well, maintaining that type 1 diabetics share an automatic bond simply because they understand the challenges of living with T1D (FIG. 2). These twelve interviews truly transformed my thinking at the time. It had never occurred to me to reach out to the T1D community for help. I became enthralled by the wealth of knowledge and support the community could potentially offer me and decided to continue my research by immersing myself in the T1D community.

Research Methodology

FOLLOWING THE EXPLORATORY INTERVIEWS, I set out to learn as much as possible about the T1D community. I employed three methods that encompassed both primary and secondary research: participatory-based practice, material-based practice and literature reviews (FIG. 3). This drawing is based on a diagram by design professors Peter Gall Krogh, Thomas Markussen and Anne Louise Bang (2016), who believe that these three modes of research are fundamental to a designer's understanding of the world. Through these methods, I embarked on a trajectory that was inherently exploratory and experimental by nature (FIG. 4). They call this "drifting," a process "of continuous learning from findings and of adjusting causes of action" (Krogh, Markussen, & Bang, 2016, p. 1).

My participatory-based practice deepened my understanding of T1D and the T1D community. In my experience, understanding the behaviours, attitudes, wants and needs of the users involved invariably leads to a more meaningful design solution. As an undergraduate student, I had previously learned the importance of familiarizing myself with the users of an interior space, primarily through an interview process. This is knowledge I carried through to this project.

As a graduate student, I have come to view participatory research as more than an interview process; it encompasses multiple methods, all of which actively involve the users of the intended design. These include observation and conversation, two ethnographic methods that

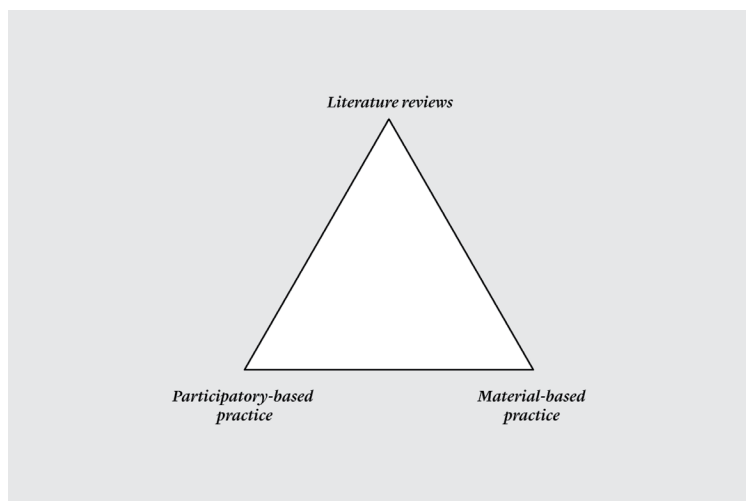


FIG. 3 Three research methods

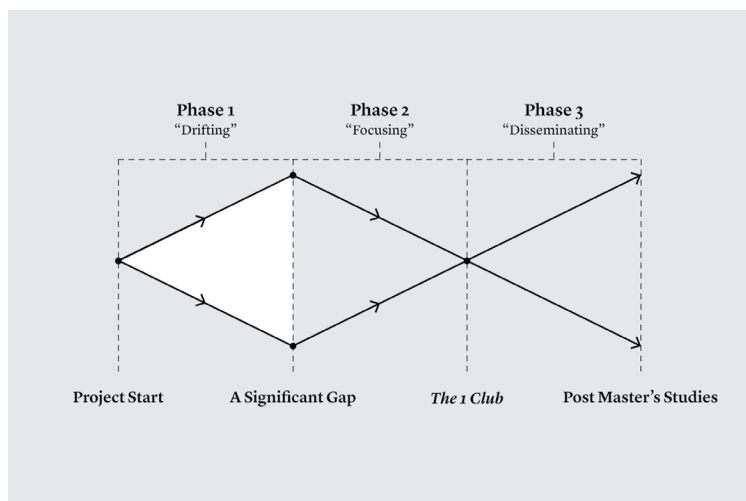


FIG. 4 Phase 1: "Drifting"

are commonly adapted by designers (Hannington & Martin, 2012). As I immersed myself in the T1D community, I gained knowledge through observing and conversing with other young adult and adult type 1 diabetics. Their experiences with T1D were used to help direct this project and later contributed to my key research findings. Additionally, as part of my participatory research, I employed co-creative practice. This included a design workshop that involved ten diabetic participants working through a series of activities specific to design and T1D.

As a “...design practice is central in generating knowledge” (Sevaldson, 2010, p. 11), my material-based practice also played a significant role in my exploration of the T1D community. I employed design as a method of inquiry that worked in tandem with my participatory research. This research encompassed the development and application of a series of small, handmade artifacts. This approach allowed me to acquire new understandings, not only through engaging with others, but also through making and sharing. My process was creative, reflective, personal and social.

In their work pertaining to material research, Bruce Hannington and Bella Martin (2012) note that “designers conduct their research through creative, critically reflective practice... utilizing their body of work to experiment and interrogate their ideas, test hypotheses, and pose new questions...” (p. 146). The artifacts that I created were a key part of my inquiry. Each artifact was presented to my colleagues and other type 1 diabetics and acted as a means of expanding dialogue around the T1D community. I developed a dynamic, generative practice of iterative making and sharing; the design of an artifact was followed by discussion and participatory research findings, which invariably informed the design of the following artifact and so forth.

My secondary research, in the form of literature reviews, consisted of collecting theory and other existing information about T1D and the T1D community. This process was necessary in order to provide support for my participatory- and material-based practices.

My dual role as both a design researcher and a type 1 diabetic placed me in a unique position. My research for this thesis was often directed by a tacit knowledge and an intuition that is both designerly and T1D specific. The introspective nature of my process was linked to heuristic inquiry. Defined by psychologist Clark Moustakas, heuristic inquiry is “an inner search for knowledge, aimed at discovering the nature and meaning of an experience” (Given, 2008, p. 3). This introspective process explicitly addresses the researcher’s involvement in the attainment of knowledge (Given, 2008). In this case, my personal lived experience with T1D was significant. It became a main component that guided my project.

T1D Community Overview

INITIALLY, MY SECONDARY RESEARCH provided an overview of the community structures that exist to aid young adults and adults living with T1D in Canada. These include diabetes clinics and educational centers, as well as non-governmental organizations such as the Canadian Diabetes Association (www.diabetes.ca) and the Juvenile Diabetes Research Foundation (www.jdrf.ca). Information is also readily available through a vast assemblage of social networks, such as Type1Nation (www.typeonenation.org) and Welcome to Type 1 (www.welcometotype1.com), and personal websites and blogs, such as A Sweet Life (www.asweetlife.org) and Sugar Free Shawn (www.sugarfreeshawn.com). At first, these resources were difficult to find; I was faced with having to sift through unwieldy amounts of information. After some time I was able to uncover crucial resources by identifying several key sources. Speaking with community leaders and organizers in person, as well as through email and Skype communications, also became invaluable. Eventually I collected a body of research including publications, online articles, personal profiles and other sources that were highly useful.

From there, I narrowed my scope and decided to focus on the human relationships and connections formed among community members. My experience as a type 1 diabetic made me aware that meaningful connections with other type 1 diabetics seemed best achieved through community structures that provide opportunities to meet face to face. My research led me to identify three groups that were particularly helpful: Young and T1 (www.youngandt1.com), Let's Talk

T1D (www.meetup.com/Let-s-Talk-T1D) and Connected in Motion (www.connectedinmotion.ca). These organizations all believe that an invaluable resource for a type 1 diabetic is another type 1 diabetic, and that the sharing of personal T1D experiences is essential to healthy diabetes management.

The Vancouver-based, volunteer-run organization Young and T1 is a group that I was immediately drawn to. Specifically targeting young adult and adult type 1 diabetics between the ages of eighteen and thirty-five, it focuses on local, collective connection. This group offers online support via Facebook and organizes activities including social events, fundraising for T1D research, group exercise, mentorship and volunteering.

I encountered Let's Talk T1D while participating in the Walk to Cure Diabetes in Toronto. This is an adult support group, hosted by the Juvenile Diabetes Research Foundation. Unlike Young and T1, Let's Talk T1D does not have an online community. Its approach is akin to a traditional drop-in support group. The conversation fostered by the gathering that I attended remained largely focused on enlightening medical aspects of T1D; I noted that topics of discussion were structured around technology failures and successes, clinic visits and long-term complications.

I became aware of Connected in Motion through my online engagement with Young and T1. This group provides activity-based, experiential programs, and works to connect like-minded type 1 diabetics to foster a culture of support. Connected in Motion's goal is to inspire and motivate individuals to obtain better mental and physical health. This is primarily achieved through activities such as hiking, biking, paddling and camping.

Research Findings

I. A SENSE OF CONNECTION

All type 1 diabetics share a common characteristic: their disease. This commonality creates a unique sense of connection among an otherwise disparate group of people. This particular attribute became very apparent to me while attending a Connected in Motion T1D weekend event in Squamish, B.C. The weekend was divided into indoor and outdoor semi-structured activities, including a presentation by the Connected in Motion group leaders, a hike around Brohm Lake and a communal campfire. There was a notable sense of harmony among us; I was amazed at how attuned we were to each other and the normalcy that came with sharing regular blood sugar testings. Often diabetics will test their sugars in private, in order to avoid drawing attention to themselves (Kendrick, “New T1D,” 2016). Many of my closest friends have never witnessed a sugar testing, something I do up to eight times daily. In contrast, drawing blood openly among fellow diabetics simply felt customary during the weekend away.

In addition to sharing a disease, type 1 diabetics also have a common language, one comprised of T1D jargon and iconography. Through primary and secondary research, I have inferred that this shared language contributes to a sense of connection within the T1D community.

T1D Jargon

Jargon is often perceived as an excluding form of language (Warren, 2015). For the T1D community however, jargon provides type 1 diabetics an opportunity to describe their disease, while simultaneously creating

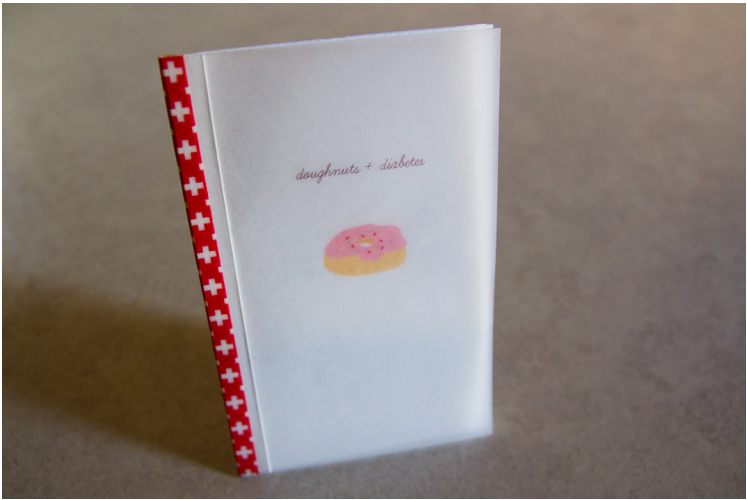


FIG. 5 Doughnuts & Diabetes



FIG. 6 Doughnuts & Diabetes

a bond between members. As a type 1 diabetic, my ability to decode this language enables me to immediately connect with fellow diabetics. In a sense, my T1D jargon acts as a vehicle into the community. A typical example of jargon includes the use of the words “low” and “high” which, to a type 1 diabetic, signify blood sugar fluctuations.* While these words have become part of my daily lexicon, they often feel ambiguous outside the T1D community, as feeling “low” or “high” could signify and be equated to a variety of different sentiments or states of being by a non-diabetic.

Interpreting diabetic jargon requires a specific lived experience and subsequent layer of understanding. As a result, it creates exclusivity among type 1 diabetics. I explored this concept through the making of *Doughnuts & Diabetes* (FIG. 5 & FIG. 6). The underlining intention of this zine was twofold: non-diabetics were to enjoy the zine at face value, while diabetics were to read between the lines, picking up on intertwined anecdotes. I included jargon as a means of distinguishing between the two reader groups. I discovered that my ability to create decipherable diabetic content created a bond between myself and the other type 1 diabetics whom I shared the zine with.

I further explored the potential of language during a co-creative workshop that was intended to bring together a group of young adult and adult type 1 diabetics to discuss the relationship between design and their disease (FIG. 7). I asked the ten participants to open an envelope revealing both a word and its corresponding definition (FIG. 8). I intentionally chose words that aligned with my understanding

* When a type 1 diabetic's blood sugar is too “high” or too “low,” he or she feels very unwell. Hyperglycemia or “high” blood sugar symptoms include frequent thirst and urination, blurred vision, fatigue and nausea. Hypoglycemia or “low” blood sugar symptoms include sweating, fatigue, nausea, shakiness and severe moodiness.



FIG. 7 Type 1 Diabetes & Design Workshop invitation



FIG. 8 Type 1 Diabetes & Design Workshop activity

of design: *generate, aspire, objective, invent, dream, compose, adapt, represent, layout* and *shape*. I asked the participants to think of the word within the context of T1D and then verbally share their thoughts with the rest of the group.

The results from this activity were poignant and revealing. As an example, when given the word “dream,” one participant spoke about her childhood dream of a cure, imagining her life without diabetes. She proceeded to say that she no longer has this aspiration, but instead views her diabetes as a catalyst for positive change in her life. Her diabetes has made her stronger and special, and she now “dreams” of mentoring children who have T1D (Janaye Marchitto, personal communication, August 12, 2015). The stories shared by each participant made sense of the selected words within the context of T1D. Each speaker transformed the words into something familiar. This familiarity created a sense of closeness between the participants; as each story was told, I witnessed other participants smiling, nodding their heads, laughing or contributing their own similar experiences to the story. While these participants were not using T1D jargon specifically, they transformed design words into a meaningful T1D narrative.

T1D Iconography

As with jargon, visual iconography has the ability to connect a group of individuals (Newman, Goulding, & Whitehead, 2012). Typical examples of imagery associated with T1D include the pancreas, as well as diabetic supplies such as blood sugar meters, insulin vials and syringes. These images often contribute to the visual content of diabetic related websites, publications, newsletters and other take-away items. On one hand, these images are easily recognizable. On the other, they symbolize the medical aspects of T1D, which for many type 1 diabetics represent the negative challenges of this disease



FIG. 9 *Embroidered Pancreas*

(Anonymous, personal communication, November 15, 2014). As a result, I felt it important to reframe current T1D iconography. To do so, I created illustrative artifacts that were inclusive of the T1D lived experience beyond the medical. My intention was to place common T1D iconography into a context more familiar to type 1 diabetics and to gauge their reactions.

Traditionally, the pancreas is represented using a didactic diagram devoid of a personal connection (“Cure,” n.d.). The *Embroidered Pancreas* artifact was a visceral response to this (FIG. 9). My intent was to reframe the pancreas, using a new visual context that integrated the more personal and tactile aesthetic of embroidery. As I discovered, recreating this organ through the methodical process of stitching allowed me to reconnect with this part of my body in a different way. The act of making served as a simple reminder that my pancreas is in fact more fragile than that of a non-diabetic. The unique relationship

I have with my pancreas forms part of my identity. When shown this object, other type 1 diabetics also contemplated their relationships to their pancreases, and emphasized the significant role this organ plays in the telling of their personal stories.

Following this, I felt it important to represent diabetic supplies as everyday objects. These necessary supplies act as everyday objects for a type 1 diabetic in a similar manner that a particular type of shoes or a wedding band might; they are familiar accouterments, part of an individual's lived experience. Unlike the shoes and the wedding band, however, they are not subject to choice. The illustrated artifact *Everyday Objects* focuses on two daily automatic activities, getting dressed and packing a bag, and the diabetic related supplies commonly associated with these (FIG. 10 & FIG. 11). The first illustration presents an insulin pump as part of a diabetic's daily wardrobe. The second illustration shows a blood glucose meter, testing strips and a juice box as critical contents of a diabetic's bag. I shared these illustrations with fellow diabetics through an online forum. They each noted that they could imagine themselves in the drawings, also having integrated their diabetes into these everyday activities. As with the *Embroidered Pancreas* artifact, *Everyday Objects* presented common attributes of T1D; a means for connecting type 1 diabetics.

II. KNOWLEDGE EXCHANGE

Up to this point I had considered myself somewhat of an expert, having lived with this disease since I was ten years old. However as I continued to immerse myself in the T1D community, I was impressed with how much new knowledge I was acquiring. The significance of knowledge exchange became increasingly apparent, as secondary sources and personal experiences shared face-to-face offered new and relevant insights.



FIG. 10 *Everyday Objects*



FIG. 11 *Everyday Objects*

Secondary Sources

The T1D community offers practical information that is both medically and non-medically related. My interaction with community structures, such as with Young and T1's Facebook page, led me to other online structures and resources. I discovered that tangible support is offered through a myriad of articles, points of action and helplines. Through my research, I became exposed to unknown information regarding various aspects of T1D care, such as financial aid opportunities, research initiatives and registration for community events.

Shared Personal Experiences

Since the fall of 2015, I have consistently engaged with members of Young and T1, both online and in person. I have found it both interesting and informative how the group's conversations naturally turn to T1D experiences. These experiences are shared through personal, spontaneous and oftentimes emotional stories that focus on topics ranging from being in a relationship with one's pump, to calculating insulin dosages in a dark movie theatre. This was unique to anything I had previously assimilated over the years through my medical team or personal research.

Unlike the participants of the exploratory interviews and the members of Young and T1, the diabetics from the group Let's Talk T1D were of varied ages. I was impressed with the resulting cross-generational dialogue and intriguing discussion. Here the concept of age versus diagnosis felt very significant. While I was the youngest member of the group, there were individuals present who had diabetes for a significantly shorter period of time than myself. I realized I was in a position of being able to offer valuable insight and emotional support to others who were older, reversing the usual conventions of mentorship.



FIG. 12 *D-Camp for Adults*

Prior to this, my experience with T1D knowledge exchange was limited to my participation in D-Camp when I was twelve years old. D-Camps provide an opportunity for children living with T1D to meet and interact with other diabetics, while enjoying an authentic camp experience. My time at camp was brief, however many of my early interviewees recalled having attended D-Camp for numerous summers. During the interviews, they reflected on the learning that came with the relationships they forged at camp (Anonymous, personal communication, December 10, 2014).

I expanded this notion to include the adult T1D community through the artifact *D-Camp for Adults* (FIG. 12). This model encompasses the memory of my camp experience. The model depicts a hypothetical gathering space, emphasizing the importance of location and physical space for a social learning process. The structure is modeled after an

actual D-Camp cabin, with the addition of a ladder on a rock face. This long ladder is a representation of a more challenging journey and camping experience, achievable by adults. When creating the artifact, I imagined a series of conversations occurring within the cabin walls, revolving around T1D. Interestingly, this hypothetical situation became a reality for me during the weekend event with Connected in Motion. Here, surrounded by the natural environment while residing in a rustic lodge, I felt comfortable sharing deeper insights and experiences with my fellow diabetics.

A different perspective to this positive correlation between my model and real life experience occurred when a photograph of the model was presented to a small group of type 1 diabetics from Young and T1. An unexpected discussion emerged, as I discovered that camping was not a particular interest for many in the group (Anonymous, personal communication, March 15, 2015). This reminded me of a seemingly obvious, but important fact: while type 1 diabetics are unified by their disease, they are a significantly varied group of people.

III. POSITIVE THINKING

Many members participating in the T1D community demonstrate positive thinking towards their disease. They view their diabetes as something to be proud of and as an integrated way of being. They also find humour in their disease, despite the seriousness of T1D. This optimistic perspective has increasingly become a key element of my work: facilitating a conscientious shift for those less positive type 1 diabetics, from T1D as a burden, to T1D as a meaningful aspect of life.

Sense of Accomplishment

Completing a difficult task with the added challenge of T1D can lead to a sense of accomplishment (pancreaswanted, “More Healthy,” 2015).



FIG. 13 *Brooching T1D*

One interviewee spoke about this when discussing the positive aspects of living with T1D:

It sounds weird but I have no idea what my life would be like without diabetes because I can't even think about it. It's just such a part of me that it becomes almost a differentiating factor... It gives you that extra sense of accomplishment. (Anonymous, personal communication, December 10, 2014)

I explored the notion of accomplishment through a series of felt brooches entitled *Brooching T1D*. Pins or brooches worn on coat lapels, sleeves or collars often represent small tokens of achievement or commitment to a cause ("Recognizing Achievement," n.d.). The felt brooches I designed used simple visual imagery connected to various aspects of T1D management including a type 1 diabetic's continual reliance on glucose, the value in knowing other type 1 diabetics and the history of T1D in regards to the discovery of insulin. The resulting

brooches were: the “JB,” representing the juice box as a commonly used method to treat low blood sugar; the “Dia-buddy,” symbolizing the connection with a friend who also has T1D; and the “Stitch” (FIG. 13), showing a pig with stitches representing pork insulin.

As designed artifacts and iconic references, the brooches evoked interest, served as reminders and provided a means to initiate dialogue. Many of the type 1 diabetics I spoke with were unaware of the original source for insulin and were initially confused by the “Stitch” brooch (FIG. 14). While wearing the “Dia-buddy” brooch to a social event hosted by Young and T1, a number of people stopped and asked me where I had bought it, as they were interested in purchasing one. The “JB” brooch helped me engage in conversations around T1D and my experience of carrying juice boxes in my purse or backpack every day as a young adult. As I wore these brooches, I felt a sense of pride related to my disease that I had not experienced before.

Way of Being

After many months of participation in the T1D community, I began to notice a trend, particularly among the community leaders. These individuals all successfully integrate their diabetes into their lifestyles. In other words, an individual’s diabetes becomes his or her way of being. Previously, I had always considered my diabetes as secondary to other seemingly more important roles in my life such as being a daughter, sister, partner, friend or student. Unfortunately, this action had often resulted in a lack of prioritization of my diabetes, in turn resulting in health-related consequences. Viewing the perspective of the community leaders, mine began to shift. I was inspired to adopt a different outlook and began to wonder as a designer how I could further facilitate this for other type 1 diabetics.



FIG. 14 The “Stitch” brooch

Humour

To me, one of the greatest aspects I have viewed in the T1D community is the humour that type 1 diabetics share regarding their disease. I have repeatedly experienced laughter as a means to counter the seriousness of T1D. In this context, humour is significant in contributing to a positive mindset.

One of my favourite T1D texts is called *The Book of Better* written by Chuck Eichten. This text is designed to help diabetics achieve better management of their disease. Eichten (2011) combines humour, graphic design and medical information to form a cohesive and “... highly accurate and accomplished map for this journey toward better” (p. 10). This book works as an excellent precedent for my own work. It not only appeals to my personal interests as a diabetic through the

inclusion of anecdotes, but also contains jokes that only type 1 diabetics would find humorous. As an example, Eichten (2011) writes, “the hole thing is a pain” (p. 71). For a type 1 diabetic, this statement acts as a double reference simultaneously to the repeated finger pricks that create small “holes” in the skin, and to the “whole” effort connected with T1D management. Inside jokes within the community work in a similar manner to T1D jargon; they connect type 1 diabetics by making light of the T1D lived experience.

As I participated in the T1D community structures, I noticed that type 1 diabetics often use humour when facing frustrating stigma around the disease. Historically, stigmatizing diabetes remains largely unchanged, particularly as it relates to sugar or alcoholic consumption and diabetes management (“Cut the Stigma,” 2014). Often diabetics feel judged by uneducated non-diabetics when eating desert or indulging in a glass of wine (Anonymous, personal communication, November 9, 2014). I have often heard type 1 diabetics retort with humour when questioned, “Should you be having that?” The artifact *Doughnuts & Diabetes*, in particular, was inspired by the way in which diabetics use humour to overcome stigma through a tongue-in-cheek approach.

Coping with Burnout

AS I WORKED THROUGH my primary and secondary research, I encountered many diabetics who shared my feelings of boredom and a general lack of momentum when dealing with the daily requirements of T1D. Additionally, I uncovered articles, profiles and blog posts written by individuals who had experienced similar sentiments. I discovered this phenomenon actually has a name; it is commonly referred to as “diabetes burnout” and is characterized by “the emotional distress that arises from living with diabetes” (Adler, 2014).

For some individuals, this burnout is experienced as a reaction to the tedious and repetitive management practices of T1D, including daily blood sugar tests and insulin adjustments (Vieira, 2014). For others, burnout takes the form of generalized feelings of anxiety or frustration that result from constant blood sugar fluctuations and the attempts to alleviate these (Vieira, 2014). Reactions to these struggles are equally varied; some individuals may purposely alter their insulin dosages or test their sugars infrequently, while others may experience unrelenting high levels of stress and fatigue. The resulting poor blood sugar control contributes to the development of long-term complications such as cardiovascular disease, kidney failure, nerve damage and vision loss (“Living with Type 1 Diabetes,” n.d.). As diabetes affects all areas of life, burnout may also negatively impact an individual’s personal relationships, socialization, education, career, economic status, or even one’s spirituality or life goals (Vieira, 2014).

As time passed, I began to recognize that a type 1 diabetic who is highly engaged in the community is motivated, inspired and empowered by what the community has to offer. This individual is more positively and actively in control of his or her physical and mental health, contributing to an increased resilience towards “diabetes burnout.”

I discovered that a sense of connection, knowledge exchange and positive thinking fostered within the community help build this resilience. Clinical psychologist and type 1 diabetic Michelle Sorensen (2015) emphasizes that empathy from others is required to overcome the demands of living with T1D. As I learned, this empathy can come from the connections created between members of the T1D community. A lack of information contributes to feelings of helplessness and anxiety, but as community members exchange knowledge with one another, they build the confidence and resourcefulness required to overcome these sentiments. Additionally, “increasing positive emotions improves health behaviours for those living with chronic disease” (Sorensen, 2015, p. 3). Individuals are more likely to prioritize their T1D as they adopt a positive mindset through forms of affirmative thinking.

A Significant Gap

DESPITE THE INCREDIBLE benefits offered by the T1D community, I have discovered that there is an overall lack of participation. As a type 1 diabetic, I had minimal connection to the T1D community prior to the onset of this project. I have realized that I am not alone in overlooking the community as an invaluable resource. While I have met many individuals who benefit from the community, I have encountered many type 1 diabetics during my research who disregard this resource. While discussing this phenomenon with these type 1 diabetics, I discovered that there are two main barriers to community support: lack of awareness of the community itself, and general disbelief in its value. I realized that a gap exists between what the perception of the community is, and what it actually can provide for a type 1 diabetic.

Clarifying My Role and Overall Aim

WITH THIS KNOWLEDGE, my research project gained its predominant focus, which was to shift the perception of the T1D community, specifically for young adult and adult type 1 diabetics (FIG. 15). Through this process, my intention was to encourage these individuals to engage in the community and indirectly defeat “diabetes burnout.” From my exploratory research, I concluded that one way to do so was to employ language as a design tool.

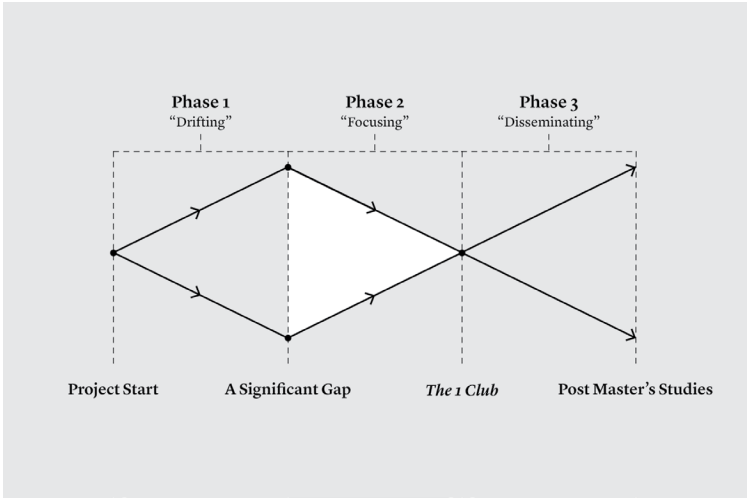


FIG. 15 Phase 2: "Focusing"

Language as a Design Tool

A tool used to re-contextualize and change meaning

WHILE MY EXPLORATORY RESEARCH yielded vast amounts of information about the T1D community specifically, it also led to another key discovery: the power of language as a transformative medium. I learned that language has the power to change the way something is perceived by shifting the context around it. Every word bears an associative connotation, thus presenting an alternative language creates new meaning. If the alternative language is familiar, it allows easy access: a means for understanding something more clearly.

My own experience provides an example of the perception-changing power of language. I had often noticed that when asked to explain T1D to non-diabetic peers, I defaulted to the standard explanation using language defined by medical professionals. Noting that this did not resonate, I was forced to change my approach and rethink the way I presented my disease to others. Instead of describing my experience through a medical lens, I interpreted my experience through the language of the everyday. For example, instead of discussing the science behind my insulin pump therapy, I would explain my need for an insulin “top up” every time I eat. This allowed me to shift perceptions from the obscure to the familiar.

Another example of the transformative power of language can be found in popular culture. A meme is defined as “a humorous image, video or piece of text that is copied and spread, often with slight variation”

(Abate & Jewell, 2001). The power of language is exemplified through each slight variation of the meme. While the subject of a meme is constant, substituted language makes its meaning infinitely variable.

A further example can be seen when examining Hoxton Street Monster Supplies in London, UK (FIG. 16). This little fantastical shop, inspired by the 826-literacy project by author Dave Eggers, is not what it appears to be. Inside the shop children purchase items such as “tinned fear” (FIG. 17), “human snot” and “neck bolt tighteners.” These monster-inspired objects create a new vocabulary and generate curiosity. However, behind its cleverly disguised façade is a passageway leading into the Ministry of Stories, a creative writing center for children. This little supply shop’s main mission is, in fact, to inspire children to read and write (D&AD, 2012, p. 574).



FIG. 16 Hoxton Street Monster Supplies



FIG. 17 “Tinned fear” from Hoxton Street Monster Supplies

The 1 Club: Re-contextualizing the T1D Community through Language

AS A DESIGNER, I employed language in its written and visual forms during the creation of *The 1 Club*, an imaginary secret society of type 1 diabetics. *The 1 Club* is representational of the actual T1D community. It serves as a means of transforming the T1D community into something more familiar and friendly, in order to appeal to young adult and adult type 1 diabetics who currently disregard the community as a resource.

WHY A SECRET SOCIETY?

As a whole, the construct of a secret society mirrors the structure of the T1D community. Secret societies are, by nature, secret congregations operating within the public domain (Axelrod, 1997). Coincidentally, type 1 diabetics live under this same shroud of mystery and go about their daily ritualistic practices within a public space, quite easily undetected by strangers, colleagues and friends. In a literal sense, type 1 diabetics covertly treat a hidden disease, making the T1D community, by default, a secret one.

I chose to expand on these inherent characteristics of the T1D community for the design of *The 1 Club*, a process referred to as “amplification” by design strategist Ezio Manzini (Baek, Manzini, & Rizzo, n.d.). Through research into imaginary and actual secret societies, I was able

to draw parallels between the language of the T1D community and that of a secret society. I then created a series of handmade artifacts that embody the essence of these parallels. The rich meaning behind the artifacts encourages a positive shift in a type 1 diabetic's perception of the T1D community.

EXPLORING LANGUAGE

From “T1D community membership” to “The 1 Club membership”

To be admitted into any secret society is to gain exclusive access to special privileges and secret knowledge shared among club members (Axelrod, 1997).

Once diagnosed, a type 1 diabetic automatically, but often unknowingly, becomes a member of the T1D community. In other words, a diagnosis is unwittingly an invitation into the community. As demonstrated through my exploratory research findings, this membership can potentially foster a sense of connection, knowledge exchange and positive thinking.

From “shared information” to “secret knowledge”

Secret societies hold secret knowledge; this information is shared exclusively among members. This privileged exchange of content results in an inclusive sense of trust and comradeship (Axelrod, 1997).

My exploratory research demonstrated that existing T1D community structures have elements that reflect the knowledge sharing of secret societies. For example, while digging through buried Young and T1 Facebook posts, I came across difficult to access information regarding a financial assistance opportunity offered by the Canadian government. Having lived with T1D for so long, I was surprised that I had never

heard of this program. Furthermore, the process of uncovering the information was not straightforward. However, scattered posts clarified the information and offered T1D group members guides to better complete the program's detailed and complicated forms. Also, through one specific post, I was able to connect with another type 1 diabetic who had recently completed the application process. She was a willing member of the T1D collective able to offer up and share practical advice as I finalized my paperwork. It was through the guidance of trustworthy sources that secret knowledge was shared and used to decrypt these government forms.

From “routine” to “ritual”

Rituals are a bond-building function of secret societies and are defined as a series of actions performed according to a prescribed order (Axelrod, 1997).

Much of my exploratory research focused on the daily, lived experience of T1D and its correlation to “diabetes burnout.” Maintaining healthy blood sugar control remains a common element uniting all type 1 diabetics. One distinct routine is the blood sugar test. This test involves pricking a finger and then placing a drop of blood on a test strip. It is necessary for a type 1 diabetic to test his or her blood sugar multiple times a day. Through this very repetitive action, every type 1 diabetic has an intimate relationship with finger pokes and blood glucose readings. Practices such as the blood sugar test are inclusive only to members of the T1D community and are a bond-building ritual.

From “Banting and Best” to “founding fathers”

Founding Fathers are the individuals who initiate a movement or institution. From the day of inception, their beliefs establish an order to be followed by all members (Axelrod, 1997).



FIG. 18 Sir Frederick Banting and Charles Best

The discovery of insulin by Sir Frederick Banting and Charles Best (FIG. 18) in 1921 was the most significant event in the history of T1D care. A fellow diabetic reminded me of their revolutionary contribution. She suggested that I display a photograph of Banting and Best in my living room, as she has done. She is often asked if they are relatives of hers, to which she replies in the affirmative. This interaction demonstrates both the familial bond she feels towards these important men and the secretive nature of the T1D community (Anonymous, personal communication, December 24, 2015). Founding fathers are mandatory to a secret society's success in the same way Banting and Best are mandatory to the lives of type 1 diabetics.

From “registration” to “allegiance”

Before one is inducted into a secret society, there is a formal swearing of allegiance to the order, in the form of an oath, absolving prior commitments to any other governing body (Axelrod, 1997).

When a type 1 diabetic registers with the T1D community, there is no formal swearing of allegiance. However, this does occur indirectly through participation. Once members partake in the various community structures, they automatically form a bond that unifies them not only to the community, but also to each other.

THE MAKING OF ARTIFACTS

This exploration of the language parallels between the T1D community and a secret society resulted in the simultaneous creation of a series of artifacts. These artifacts serve as the visual iconography for the imaginary secret society of *The 1 Club*.

The idea of membership is introduced through both the membership letter (FIG. 19 & FIG. 20) and the poster artifacts (FIG. 21). The letter serves as a welcome for newly diagnosed type 1 diabetics to *The 1 Club*. This artifact intends to provide a sense of comfort, rather than induce the fear and stigma that is often associated when a diabetic is first diagnosed. The poster works to spread awareness of and entice membership to *The 1 Club*. Both the letter and the poster are written in a subtext comprehensible to type 1 diabetics only. If intercepted by a non-diabetic, cryptic messages such as the number “1” and “blood-testing kindred” would not reveal the identity of the intended recipients. This purposeful encryption creates a secret knowledge exclusive to type 1 diabetics.

Dear 1,

Welcome to The 1 Club. Your curiosity
has led you to us.

We are a secret society of blood-testing
kindred. Hidden in plain sight, until
today. This letter recognizes your
readiness to self-revitalize.

Strength is in our numbers, but only
if we act as 1. It is our belief that
our bond is of vital importance to our
collective wellbeing. Sharing wisdom is
at the forefront of our secret order.

If you agree, lift a finger in honour
of our forefathers Banting and Best, and
swear to and sign the Oath of Optimism.

Secretly yours,

The 1 Club
Every 1 Welcome



FIG. 20 *The 1 Club* membership letter

Every secret society has a visual identity. The next artifact, a hand-embroidered crest representing *The 1 Club*, embodies the language of rituals and founding fathers (FIG. 22 & FIG. 23). The crest presents a hand with its index finger pointing upwards. Above the finger marked with an x floats a drop of blood, symbolizing the daily ritual of blood sugar testing. On either side of the hand are the discoverers of insulin, Sir Frederick Banting and Charles Best, the society's appointed founding fathers. The crest contributes to the visual iconography of *The 1 Club*, helping to cultivate a sense of connection among its members.

The 1 Club intentionally asks that its members swear and sign the Oath of Optimism (FIG. 24) as a form of initiation, solidifying their commitment to the order. The Oath artifact specifically addresses the importance of each individual member to the society's collective whole.

**IT
TAKES
1
TO
KNOW
1**

Every 1 Welcome

– 12 Mercer Street –



FIG. 21 *The 1 Club* poster



FIG. 22 *The 1 Club* crest



FIG. 23 *The 1 Club* crest

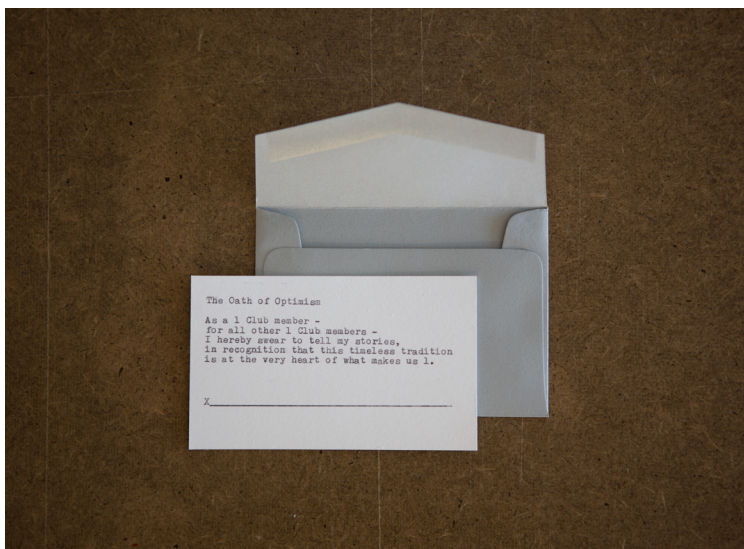


FIG. 24 *The 1 Club* Oath of Optimism

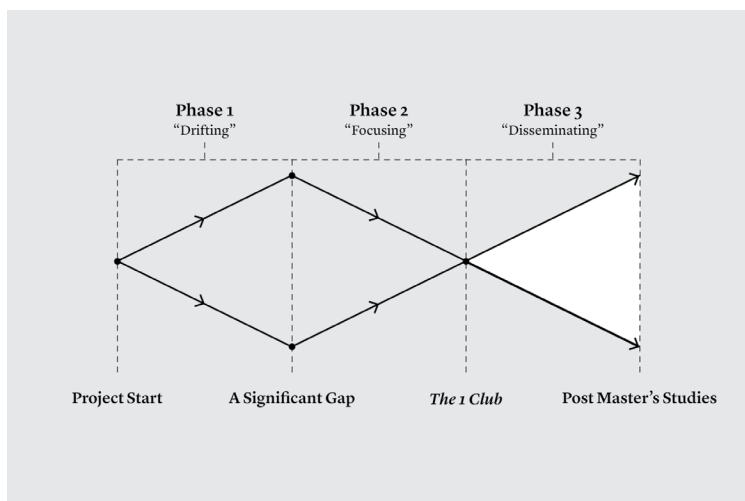


FIG. 25 Phase 3: “Disseminating”

Language was incorporated throughout the design and creation of these four artifacts and became an integral part of my making process. The concepts of membership, secret knowledge, ritual, founding fathers and allegiance became intertwined with each object. By using the language of a secret society, the dialogue around the T1D community expanded. Non-diabetic peers in particular were more easily able to provide feedback, as this language was familiar to them.

As I worked through my making process, I began to view each artifact as an interwoven component of a larger picture: a story about *The 1 Club*. I recognized story as a transferable and memorable design tool. This marked the beginning of the final phase of my project (FIG. 25).

Story as a Design Tool

A tool used to send a memorable message

THE 1 CLUB artifacts were designed using the written and visual language of a secret society as a means of shifting type 1 diabetics' perceptions around the T1D community. For the type 1 diabetics who are unaware of the community, however, it became necessary to elicit an initial awareness and acquaint them with the community structures. I decided to pursue the use of story as a design tool to bring awareness of the community to these individuals.

The act of telling a story builds an emotional connection between the storyteller and the audience. A story can create a significant and memorable message when effectively related through a particular language. A well told story draws the listeners in and leaves a lasting impression through the emotive quality of the language and narrative (Orrick, 2015).

As a type 1 diabetic, I have relied on my intuition during the process of creating the story of *The 1 Club*. As a designer, I have chosen to deliver this story through animated illustrations, drawing on the language parallels between the T1D community and a secret society. Here, elements within a frame, as well as the sequencing of frames, contribute to building an effective and moving response. My intent is for the animation to help send a persuasive message that encourages type 1 diabetics to discover and participate in the T1D community.



FIG. 26 Still from *The 1 Club* animation

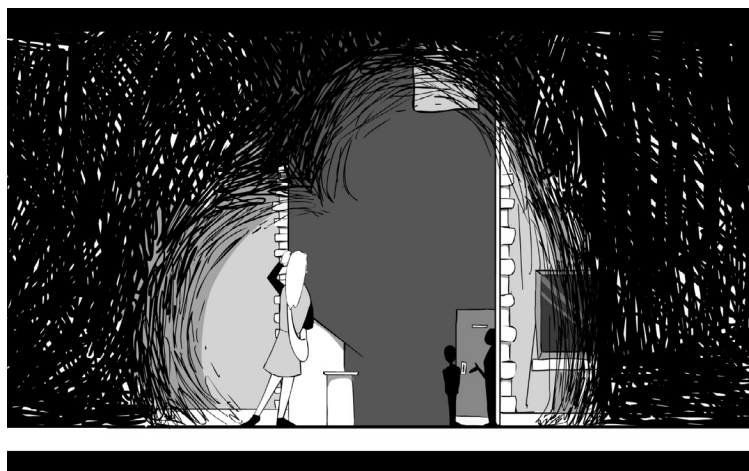


FIG. 27 Still from *The 1 Club* animation

The 1 Club: Promoting the T1D Community through Story

MY SHORT STORY, relayed through animation, depicts a young woman who is invited to become a member of *The 1 Club*. It opens with the mysterious arrival of a letter. Upon reading the letter, the young woman is intrigued by its opening message: “Dear 1. Welcome to *The 1 Club*. We are a secret society of blood-testing kindred” (FIG. 26). She glimpses at the bottom of the page and notices a stamp that shows a hand with its index finger pointed upwards above an address. The finger, with a drop of blood hovering over it, is marked with an x. As the young woman begins to piece things together, she grabs her jacket and heads out in search of *The 1 Club*. Subsequently, the young woman approaches the entrance of a building, stops, and notices two people go in (FIG. 27). She quickly walks to the door and knocks on it twice. A peephole slides open, a serious face appears and then a voice mumbles “password.” She holds up her own marked finger and the person on the other side of the door chuckles. The door opens and she is led into the brightly lit and cheerful interior of *The 1 Club*. The animation concludes with a neon sign hanging above the door that reads, “Every 1 Welcome,” the society’s motto.

This simple story developed from my earlier artifacts depicting elements of *The 1 Club*. These artifacts were employed as essential storytelling elements and a means of creating a compelling narrative. The artifacts and the animation depict an imaginary secret society intended to capture the curiosity of fellow type 1 diabetics, while generating

excitement around the T1D community. The motto of *The 1 Club*, “Every 1 Welcome,” suggests a sense of exclusivity by only welcoming type 1 diabetics to the society.

The animation’s main character has been created to resonate with type 1 diabetics. The young woman’s story is intended as a catalyst for others to consider joining and actively participating in the existing community structures. The story of *The 1 Club*, as conveyed through the artifacts and the animation, is unique. Unlike conventional material provided to type 1 diabetics, *The 1 Club* uses fictional storytelling as a vehicle to help understand the significant contribution and sense of support provided by the T1D community.

Reception of *The 1 Club*

WHILE I HAVE already shared the concept of the secret society to a number of diabetics, I have yet to present *The 1 Club* in its entirety. In the coming months, I will introduce type 1 diabetics to *The 1 Club* through exhibitions, a conference and T1D community talks. I also plan to connect type 1 diabetics to the story of *The 1 Club* through the future development of an online platform.

Thus far, the reception of my work has been highly positive. The diabetics I have spoken with believe that *The 1 Club* offers a new perspective on T1D and the T1D community. I am happy to note that very little clarification was needed for these individuals to grasp the concept. Based on these positive responses, I have good reason to believe that the animated story of *The 1 Club* and its artifacts will be effective communication tools. My final hope is that type 1 diabetics who are unaware of or disbelieve in the power of the community structures will come to see these in a different light, and consequently build resilience towards “diabetes burnout” through active participation in the community.

Post Master's Studies

THROUGH DISSEMINATION of *The 1 Club*, I expect my project trajectory to alter once again. I am interested in developing and expanding the story through the inclusion of other artifacts that will be created or supplied by fellow diabetics. Perhaps this story might become the introduction of an archive of T1D secret society relics. Or perhaps the telling of the story of *The 1 Club* will open up completely unanticipated dialogue and shared knowledge that will continue to foster connection among type 1 diabetics.

Concluding Thoughts

MY THESIS HAS been unexpectedly non-linear. When I first began the process, I had clear intentions which eventually dissipated. I consistently found myself in the middle of a chaotic and unexplained research trajectory that required personal reflection and instinct to resolve. A great deal of my insight came during these periods of reflection. This process has made lasting changes to the way in which I view myself as a designer. I now more clearly comprehend the role of making and designing as modes for generating new knowledge.

Through this project, I have not only grown as a designer, but also as a type 1 diabetic. I believe, over the course of my master's degree, that I have developed resilience against "diabetes burnout" through the personal engagement I had with the T1D community. The community benefits of a sense of connection, knowledge exchange and positive thinking have greatly contributed to this. The feelings of boredom that I experienced around the start of my thesis have dissolved. Most importantly, my diabetes has once again become a priority. This is further inspiration for me to continue to push this project forward, in the hopes that other young adult and adult type 1 diabetics experience the same resilience against burnout. Furthermore, I hope other designers will build from this research using the design tools and methods of community, language and story to aid others living with chronic diseases.

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Figure References

FIG. 16 The Hoxton Street Monster Supply Shop

Hoxton Street Monster Supplies. (n.d.). Retrieved from <http://www.wemadethis.co.uk/work/branding/project/index.php?id=1807>

FIG. 17 “Tinned fear” from The Hoxton Street Monster Supply Shop

Hoxton Street Monster Supplies. (n.d.). Retrieved from <http://www.wemadethis.co.uk/work/branding/project/index.php?id=1807>

FIG. 18 Sir Frederick Banting and Charles Best

Frederick Banting. (n.d.). Retrieved from https://en.wikipedia.org/wiki/Frederick_Banting

Glossary

blood sugar

Blood sugar or blood glucose is a sugar that is transported through the bloodstream to supply energy to all the cells in the body. This sugar is made from the food an individual consumes.

blood glucose meter

A type 1 diabetic tests his or her blood sugar levels using a blood glucose meter. This is done by pricking a finger, then placing a drop of blood on a test strip. It is necessary for a type 1 diabetic to test his or her blood sugar levels multiple times a day.

high and low

When a type 1 diabetic's blood sugar is too high or too low, he or she feels very unwell. Hyperglycaemia or high blood sugar symptoms include frequent thirst and urination, blurred vision, fatigue and nausea. Hypoglycaemia or low blood sugar symptoms include sweating, fatigue, nausea, shakiness and severe moodiness.

insulin

Insulin is a hormone produced in the pancreas that regulates the amount of glucose in the blood. A type 1 diabetic relies on a synthetic form of insulin for life, as his or her body no longer produces any insulin.

pen, syringes and insulin pump

A type 1 diabetic may use a pen, syringes or insulin pump to administer insulin.

carbs and carb counting

Most foods contain carbs. A type 1 diabetic must count the carbohydrates he or she consumes in order to attempt to accurately calculate their required amount of insulin. Carb counting is usually an approximation, as many foods and food combinations are impossible to measure.

endocrinology

The branch of physiology and medicine concerned with endocrine glands and hormones. A type 1 diabetic visits their endocrinologist for medical advice pertaining to the daily management of their disease.

