

#BUTYOU DONT LOOK SICK

Advocacy Awareness Project for Invisible Illnesses and Disabilities, in the Work Environment

**AUTOIMMUNE DISEASE
INVISIBLE ILLNESS
CHRONIC ILLNESS**

I'm not ashamed of my illness or my knowledge

I'M ASHAMED AT THE LACK OF UNDERSTANDING PROLONGED SUFFERING AND INADEQUATE CARE

We are not ashamed of asking when we cough up. Nor should we be silent martyrs.

We deserve change #GenieUs @AqeneAtsila @RogueAutoimmuneMummy

MoreAwareness EarlierDiagnosis BetterMedicalSupport

The worst thing you can do to a person with an invisible illness is making them feel like they need to prove how sick they are.

@helpthemrise

It's hard to explain to someone who has no clue. It's a daily struggle to be in pain or feel sick on the inside while looking perfectly fine on the outside.

Please help spread awareness of invisible illnesses like: Crohn's, PTSD, Anxiety, Bipolar, Depression, Diabetes, Lupus, Fibromyalgia, MS, ME, Arthritis, Cancer, Heart Disease, Epilepsy, M.D., and more!

Treat people with kindness and compassion. Never judge what you don't understand.

NORMAL PERSON'S PAIN SCALE

1 No Pain, 2-3 Slightly Painful, 4-5 Hurts, 6-7 Hurts a Lot, 8-9 Agony, 10 Un-Bearable

POONIE'S/CHRONICALLY-ILL PERSON'S PAIN SCALE

1 No Pain, 2-3 Slightly Painful, 4-5 Hurts, 6-7 Hurts a Lot, 8-9 Agony, 10 Un-Bearable

I'm not faking being sick, I'm faking being well

HELLO I'M MORE THAN MY ILLNESS

I AM NOT A SICK PERSON. I AM A PERSON MANAGING AN ILLNESS.

The Unbroken Smile

0-10 SCALE OF PAIN SEVERITY

Severity	Description of Experience
10 Unable to Move	I am in bed and can't move due to my pain. I need someone to take me to the emergency room to get help for my pain.
9 Severe	My pain is all that I can think about. I can barely talk because of the pain. My pain is so severe that it's hard to think of anything else. I'm crying and feeling an itch.
8 Intense	My pain is so bad that I can't do any of my usual activities.
7 Unmanageable	I think about my pain all of the time. I give up many activities because of my pain.
6 Distressing	I think about my pain most of the time. I cannot do some of the activities I need to do each day because of the pain.
5 Distracting	I am constantly aware of my pain but I can continue most activities.
4 Moderate	My pain bothers me but I can ignore it most of the time.
3 Uncomfortable	I have a low level of pain. I am aware of my pain only when I pay attention to it.
2 Mild	

Hey! So... Uhm... I Have this thing called a **CHRONIC ILLNESS**

FOR DAYS WHEN YOU DONT HAVE THE ENERGY TO SAY IT.

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PLEASE READ THIS

If the person you care about has been diagnosed with a form of dysautonomia, they have a disorder of the autonomic (autonomic) nervous system. Symptoms usually range from mild to disabling, but in some cases, can be life-threatening. Because most of the problems occur inside the body, dysautonomia is an "invisible illness." People with dysautonomia need your help.

- **Help them stay hydrated.** Many people with dysautonomia have trouble maintaining blood pressure. Drinking water is key.
- **Some family members may think it's just a bad mood.** They are "making this up." The truth is, dysautonomia is an internal medical condition that needs to be taken seriously.
- **Plan for meltdowns.** Your family member or friend may become very irritable and sensitive to their feet, touch, and before a big night out or a special event, and they may not be able to control it. It's important that you are supportive and willing to be flexible when they don't feel well.
- **Be open to learning.** Signs that indicate they might need to visit a doctor, or be hospitalized. This may include inability to heat, eat, drink, shower, and being in large crowds.
- **They may not be able to do all of the things they used to do** including shopping, household chores, and attending big parties.

Your family member or friend is facing a difficult medical battle. There is no cure for dysautonomia. Treatments are aimed at managing symptoms and improving function, where possible. It often takes time to find the right doctors and combination of treatments to improve health. The people who face this condition may struggle with feelings:

C.A.R.E. Make Fibromyalgia Visible

o n t r i b u t e e d u c a t e

Fibromyalgia

Chronic Fatigue Syndrome (CFS)

Muscle Pain

Chronic Pain

PEOPLE START TO HEAL ONCE THEY FEEL HEARD.

HOW TO SUPPORT A LOVED ONE STRUGGLING WITH A CHRONIC ILLNESS

TELL THEM THAT YOU CARE. BE GENUINE AND SINCERE. ASK "HOW CAN I HELP?" AND BE WILLING TO LEND A HAND ESPECIALLY WITH THINGS LIKE CLEANING AND COOKING.

TALK TO THEM, READ THEM A BOOK, TAKE IT SLOW. BE COMFORTING. SUGGEST A MOVIE. BE GENTLE WITH YOUR WORDS.

EVEN JUST SOMETHING AS SIMPLE AS LETTING THEM VENT THEIR FRUSTRATIONS CAN MAKE A HUGE DIFFERENCE.

IF THESE THINGS DON'T WORK, SIMPLY ASK IF THERE IS ANYTHING YOU CAN DO FOR THEM.

IF NOTHING ELSE, SIT CLOSELY, HOLD THEIR HAND AND TRY TO BE REASSURING. BE PRESENT KNOWING THAT SOMEONE IS THERE AND THEY CARE IS SO SPECIAL AND MEANINGFUL. TRYING IS WHAT MATTERS THE MOST. EFFORT IS EVERYTHING.

WHICH MED DO YOU NEED TODAY?

*Images above from Instagram, Pinterest, Google research for sample/example use only.

As we approach **Invisible Disabilities Week (Oct 14th – 20th, 2018)** it is important to create an awareness to and issue that is on the rise in the United States. By definition an Invisible illness or disability is “*a physical, mental or neurological condition that limits a person’s movements, senses, or activities that is invisible to the onlooker.*” (1) Persons with these types of disabilities struggle everyday, in the workforce and in life. To often being at the mercy of an illness causes individuals to not be able to maintain jobs. For so many reasons, the long term effects of this hinder their overall quality of life. The hope of this project is to support the mission and vision of: The Invisible Disabilities® Association by *extending outreach, increasing awareness, and better education, of invisible illness and disabilities (1) and is focused on doing so in the work environment.*

The Invisible Disabilities® Association: Mission & Vision

The Invisible Disabilities® Association is about believing. We believe you! The frequently invisible nature of illness and pain may lead to disbelief about that illness or pain by those surrounding the person who lives daily with invisible disabilities. This disbelief can lead to misunderstandings, rejection by friends, family and health care providers. It may also lead to accusations of laziness or faking an illness. We are passionate about providing awareness that invisible illness, pain and disabilities are very real! Our mission is to encourage, educate and connect people and organizations touched by illness, pain and disability around the globe. Envision with us, a world where people living with illness, pain and disability will be Invisible No More®. (2)

About The Invisible Illnesses

Invisible Illnesses and all that accompanies them are variable to the individual. Things like pain scales, emotion charts and spoon theories have become the norm for communicating how a person is feeling, especially when their disability can not be seen and their words seem to not be enough. Tools such as these have proven helpful to create awareness in the invisible illness world but it has also been discovered that often a persons status can not always be communicated effectively through the use of these modalities. Often times people with invisible illnesses and disabilities have a hard time asking for help, they push themselves to their limits and forget to check in on their own well being. This can cause them to encounter issues in the workplace a the lack of understanding among their coworkers does not help. The opposing side to that is constant need to explain or justify on these scales and others like these can be discouraging. This especially applies in the work place. When the simple statement: “**Today I am battling**” should be enough.

This project hopes to enhance awareness around invisible illness in the work place.

Citations:

1. <https://invisibledisabilities.org/what-is-an-invisible-disability/>
2. <https://invisibledisabilities.org/about/aboutida/>

About The Project

Create a double sided token, that allows for visual communication for individuals with invisible illnesses. This can be placed on a persons desk and also carried with them and will aid in them with the ability to non-invasively serve as a tool to support how they are feeling that day.

Side One: shares a message “I am grateful for days like this.” (For when a person has a good day)

- To the individual this is a good reminder that: good days do happen.
- To others this lets them know to: remember me now, when I am at my best self.

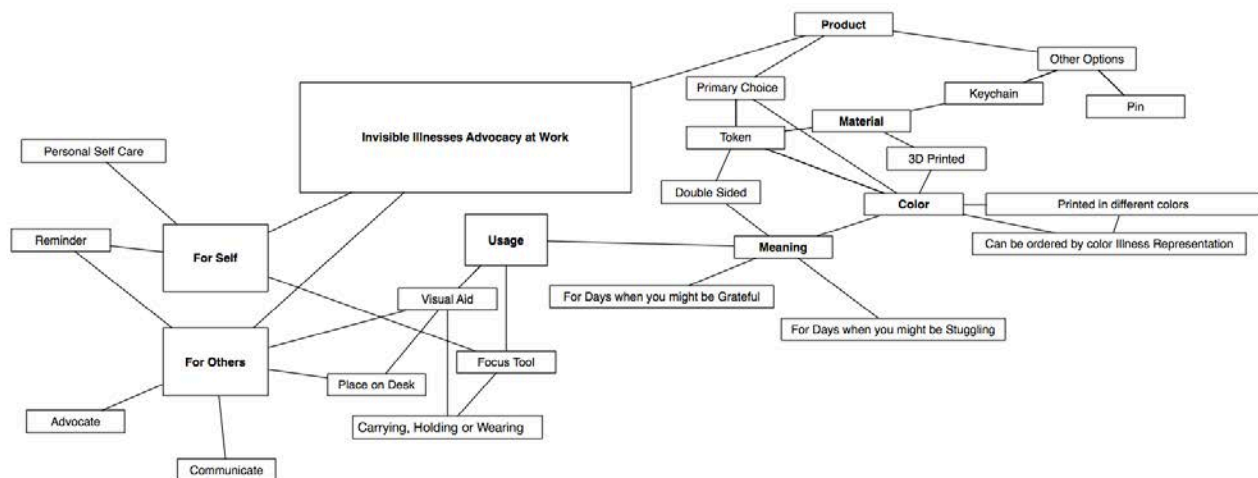
Side Two: communicates to “Be kind, I am battling today. (For days of struggle.)

- This communicates to the self to: not be to hard on yourself and give yourself a break today.
- It is a visuals reminder to others to: be a bit gentle with you today.

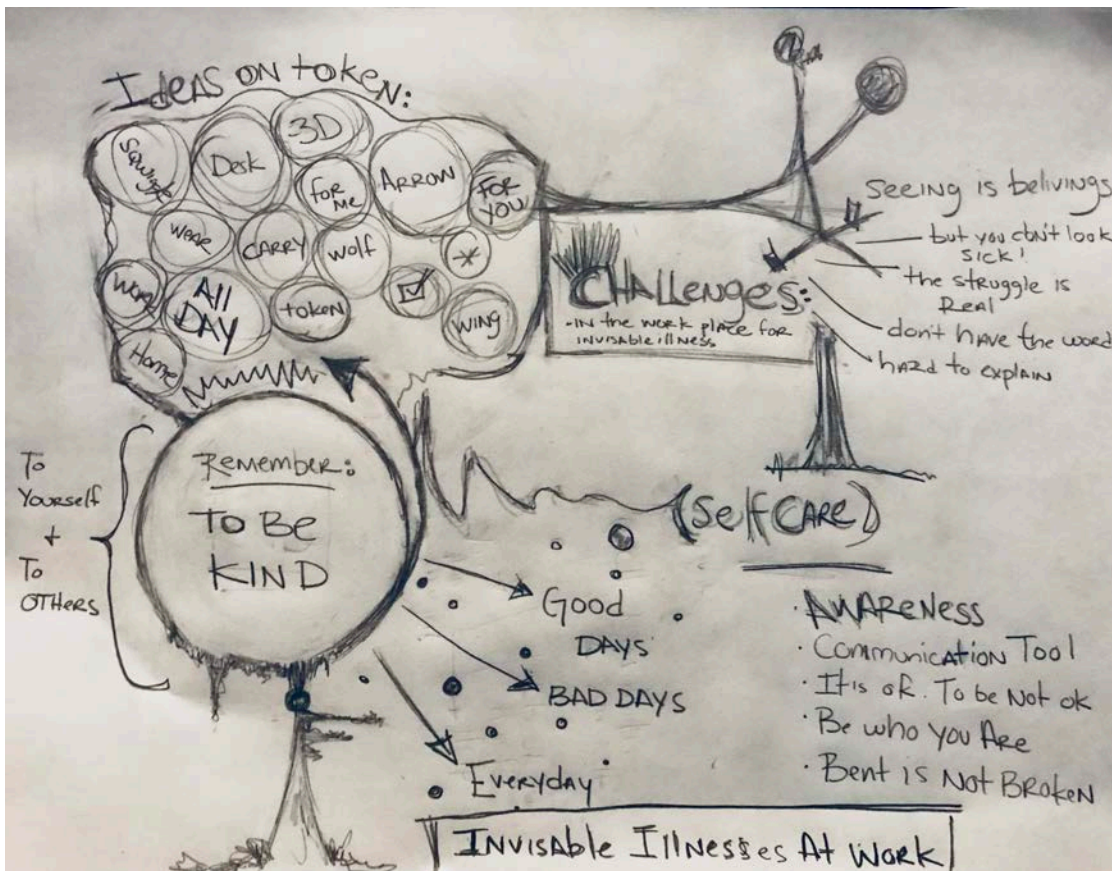
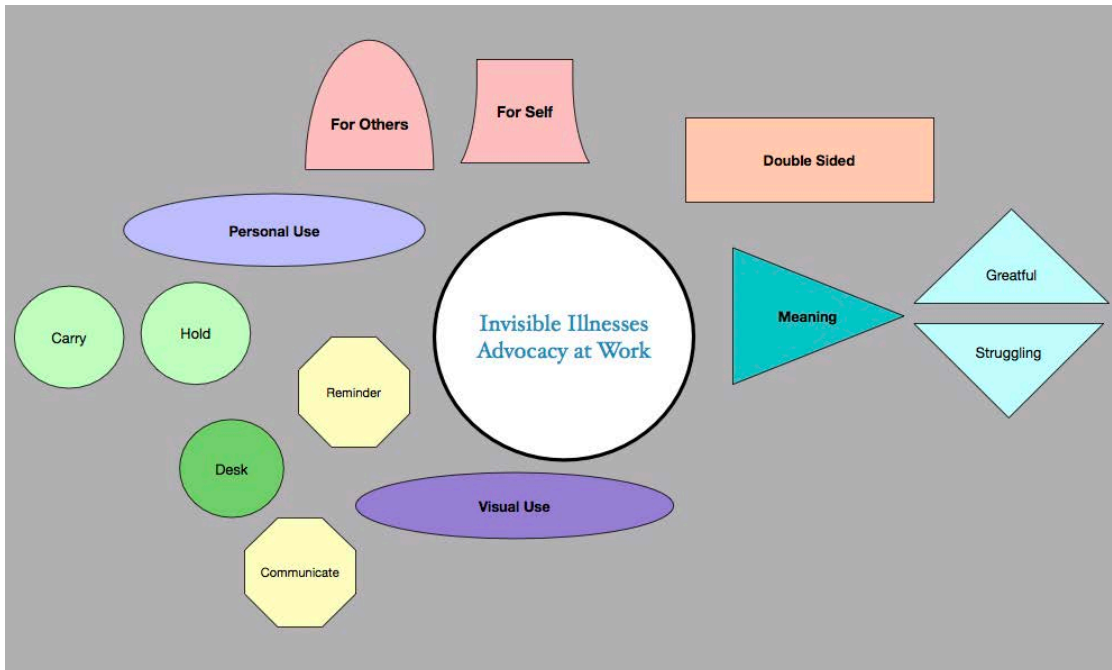
Usage

The token can be carried or held in ones hand. Carriers are reminded to check in with themselves daily. This allows a person to feel both sides, remembering that some days might be tough but there are also good days ahead to look forward too.

The token can be placed on an individuals desk. The visual presence of the token can assist others in understanding what is going on and initiate opportunities to lend support. Through the use of this token there is no need for unveiling of specifics, a feeling of obligation to tell your coworkers your life story or defend oneself. This token bypasses the opportunity for criticism or judgement, pain scales, faces, emojis. It communicates a message for you, helping to build a bridge between what some cannot see and what others know is there.



BrainStorming



TinkerCad Samples:

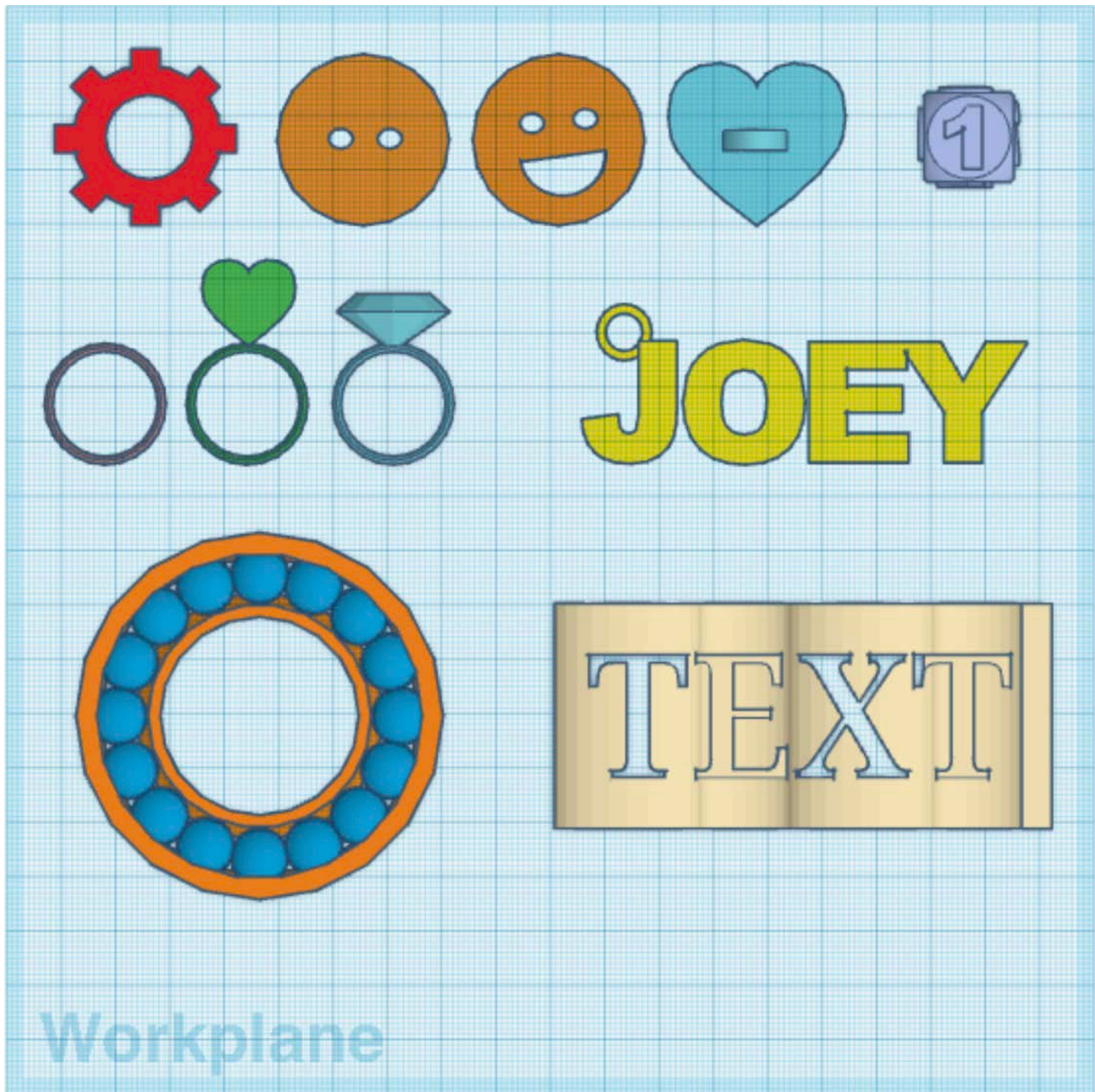


Prototyping

During this part of the project I tested size, shape and color options.



Workshop Tests



Iterations

During this part of the project I tested size, shape functionality and color options.

- Color options will help to identify invisible illnesses. (example: Purple, Lilac for Lupus Awareness)
- Added in a loop hole for a keychain
- Parts snap into each other like puzzle pieces. One piece is the base to be left on a desk and the second can be carried to an from work. Snapped in upon arrival at work station and removed when leaving.



Research for Iterations

The Heart Project













Raising Awareness For Mental Health & All Mental Illnesses




On July 10th - 15th join The Heart Project to spread & raise mental health awareness; to not hide behind shame & stigma.

Draw hearts on your wrist/arm/ankle using the official awareness ribbon colors. Take a photo & share it here and on your profile.

Hash tag it #TheHeartProject

Some Examples - ALL Mental Illnesses are Included:

					
Depression	Anxiety	Eating Disorders	Suicide Survivor	Bipolar	D.I.D
					
Self Harm	PTSD	Schizophrenia	O.C.D	B.P.D	Supporting

   [Mental Health and Invisible Illness Resources](#)

Invisible Disabilities Week

For ALL mental illnesses, and invisible illnesses/disabilities

On October 15 -21 join Invisible Disabilities Week and raise awareness. Draw smiles on your wrist/arm/ankle using the official awareness ribbon colors. Take a photo & share it here and on your profile. Hash tag it #IDW17 #TheSmileyFaceProject

Some examples: - ALL Invisible Disabilities are included:

						
Chronic Illness	Mental Illness	Rare Disease	Eating Disorder	Heart Condition	Dissociative Disorder	IBD
						
Personality Disorder	Autoimmune Disease	Anxiety Disorder	Learning Disability	Mood Disorder	Genetic Disorder	Supporting (Black Outline)













   [Mental Health and Invisible Illness Resources](#)




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Some examples: - ALL Invisible Disabilities are included:

						
Dyslexia (Silver)	Trigeminal Neuralgia	SPD	Cystic Fibrosis	Scleroderma	Narcolepsy	Parkinson's Disease
						
PNES	Gastroparesis	Diabetes	HIV/AIDS	Chiari Malformation	Allergy	Supporting (Black Outline)











   [Mental Health and Invisible Illness Resources](#)


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Some examples: - ALL Invisible Disabilities are included:

						
Cancer	Tourette Syndrome	Vertigo (gold/silver)	Scotiosis	Sjögren's Syndrome	PCOS	Hemophilia
						
Ankylosing Spondylitis	Dementia	Dystonia	Myasthenia Gravis	CVS	Osteoarthritis	Supporting (Black Outline)















   [Mental Health and Invisible Illness Resources](#)




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Some examples: - ALL Invisible Disabilities are included:

						
Chronic Pain	DID	Lyme Disease	Addiction	Migraine	Schizoaffective Disorder	POTS
						
OCD	CRPS	Anorexia	Celiac Disease	ODD	R. Arthritis	Supporting (Black Outline)




   [Mental Health and Invisible Illness Resources](#)


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Some examples: - ALL Invisible Disabilities are included:

						
SREAT	Intracranial Hypertension	GERD	Stiff Person Syndrome	Pulmonary Hypertension	Histrionic Personality Disorder	CSF Leak
						
Pituitary Disease	Dravet Syndrome	OCPPD	Dandy Walker Syndrome	MCTD	Pulmonary Fibrosis	Supporting (Black Outline)

   [Mental Health and Invisible Illness Resources](#)

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Some examples: - ALL Invisible Disabilities are included:

						
EDNOS/OSFED	Transverse Myelitis	Distematomyelia	Degenerative Disk Disease	CPTSD	Syringomyelia	MCAS
						
Eosinophilic Esophagitis	Arrested Development Disorder	Marfan Syndrome	Peripheral Neuropathy	Psoaritic Arthritis	Dysautonomia	Supporting (Black Outline)

   [Mental Health and Invisible Illness Resources](#)

Citation: <https://www.facebook.com/MentalHealthandInvisibleIllnessResources/photos/you-are-now-welcome-to-post-your-photos-please-read-below-before-commenting-all-/1131816610252091/>

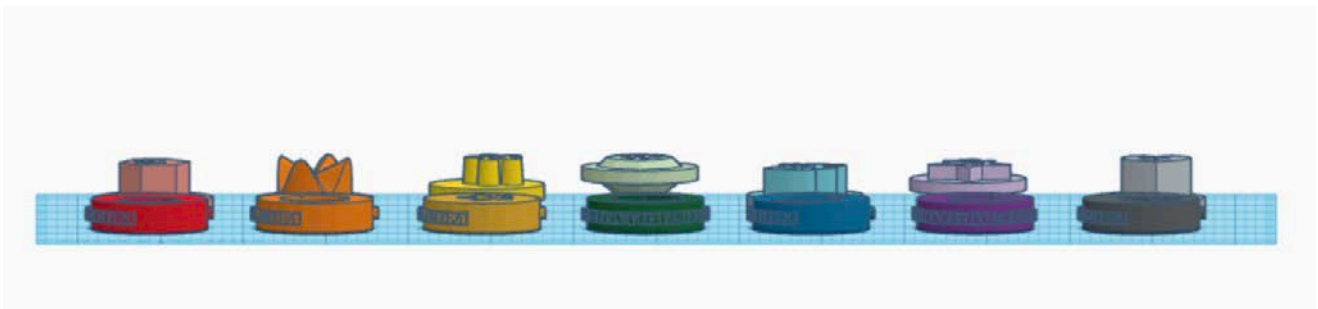
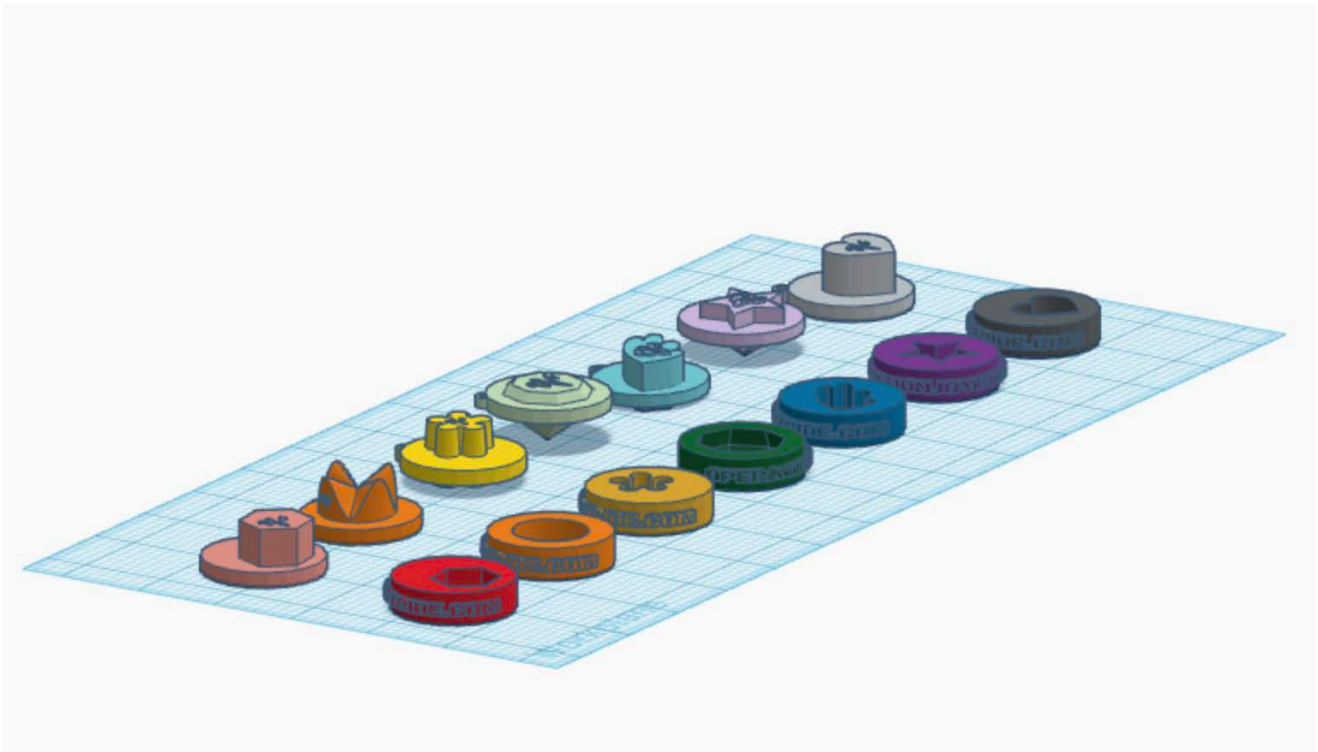
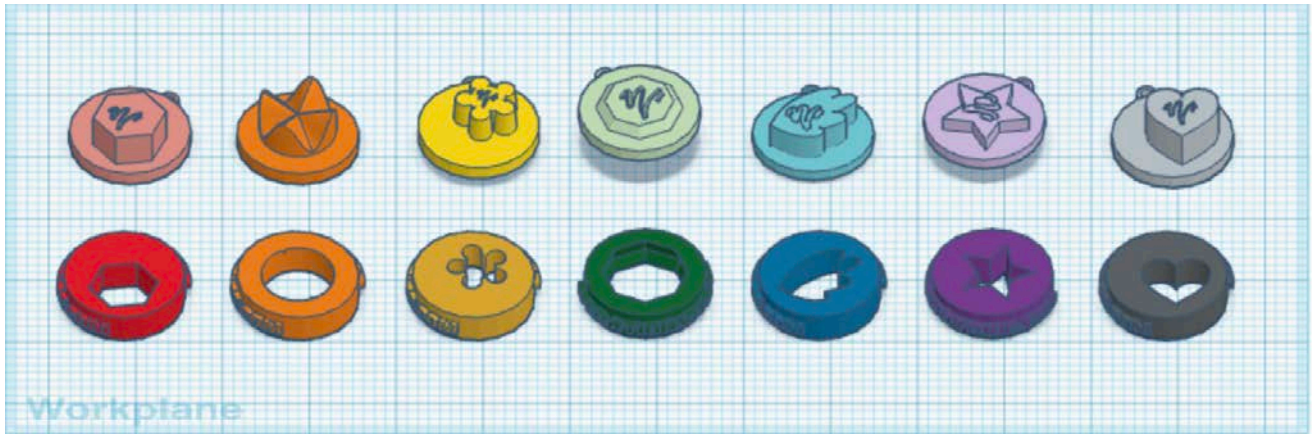
Iterations

During the Iterations phase I took the resources collected, choose colors and planning for some invisible illnesses. Currently the color designs cover multiple illness, which in a lot of ways I think is good, allowing a person to use this tool as a way to visually communicate about their illness while not having to feel like it is completely exposed. On the bases there has been added in a website wrap for a domain where people can go and find out more information about this project, learn more about other community giving projects.

Here is the first run of what that looks like.

1. Diamond/ Mountain to be printed in light green and the the base for that in a dark green
(Covering some examples (include but are not limited to: Gastroparesis, Celiac, Mental Illness, Depression and Mood Disorder)
2. The Wing to be printed in a Teal and the base to be in a darker blueish color
(Covering some examples (include but are not limited to: Trigeminal Neuraliga Anxiety, PTSD, OCD, Allergy, Tourette syndrome)
3. The Heart to printed in a Light Silver and the base to be in a Darker Gray
(Covering some examples (include but are not limited to: Personality Disorder, BPD, Dyslexia, OCPD)
4. The Star to be printed in a light Purple and the base to be a dark purple
(Covering some examples (include but are not limited to: AutoImmune Disease, Eating Disorders, Chronic Illnesses, Chronic Pain, Migraines, Cancer)
5. The hex to be printed in a light pink and the base to be a Red
(Covering some examples (include but are not limited to: heart conditions, HIV/ AIDS, Hemophilia)
6. The Flower to be printed in a light Yellow and the base to be a dark yellow
(Covering some examples (include but are not limited to: Self Harm)
7. The Wavy top to be printed in a light Light Orange and the base to be a Orange
(Covering some examples (include but are not limited to: Suicide Survivor)

Results



Things I hope to accomplish in the Future of this project:

- More information on the website including a way to purchase and customize.
- QR codes for resources about how to be a better supporter.
- Work out color choice log
- Make them stackable
- Packaging.

This project is very personal to me and I hope to use this as a way to give a voice to all my friends with invisible illnesses. YOU ARE SEEN, YOU ARE GREAT, AND YOU ARE LOVED.

OPERATIONJOYRIDE.COM

THANK YOU.