

ELEVATOR PITCH

How to share YOUR story in 2 minutes

Why share?

Your story, unique to you, can help others connect to rare disease + Galactosemia, and further the discussions around what can be done to help people with Galactosemia receive understanding of their disease + treatment.

What to share?

Sometimes you've got two minutes. You CAN share in an IMPACTFUL way in that amount of time. It's important to know how + leave your audience with a call to action.

Where to share?

It's important to know who your audience is, why they are listening, and how you can ask them to be more involved. This will affect how you enter into your "elevator", what you discuss on the ride, and how you exit.

The way you share on social media will be different from how you share on a public forum for rare diseases or in a congressmen's office.



Why you should share

Sharing YOUR story is one of the most impactful ways you can bring more awareness around Galactosemia, and rare disease in general. There are many things happening right now, where your story matters- but knowing HOW to share, WHAT to share, and WHERE can be overwhelming.

When I started GLOW, one of the first things someone sat down to talk to me about was my "elevator pitch". Essentially, it boils down to, if you have only the time it takes to ride an elevator with someone, how will you grab their attention, and leave them remembering your story + call to action?

If you've only got 2 minutes, what do you share and why?!



What are your goals in sharing?

Why you are sharing should have a lot to do with what you share and how. If you start sharing without a goal in mind, then the person listening will not know why you are sharing with them or what you are asking of them by sharing.

Think about these examples:

- Is it to raise awareness, so that your child's diet and special needs are taken seriously in a certain setting?

If this is the case, then you will want to focus on why the diet is so important, what happens if the diet isn't followed, and other complications of the disease. The call to action for the listener would be to ensure your child is kept safe by paying extra attention during meal times.

- Are you seeking to fundraise?

If this is the case, then you will want to focus on the impact of disease and the lack of funding from other sources. The call to action for the listener would be to donate on behalf of a given organization that would provide for a need not met otherwise.

- To build community with other special needs families?
- Is it to raise policy issues?

What should you share?

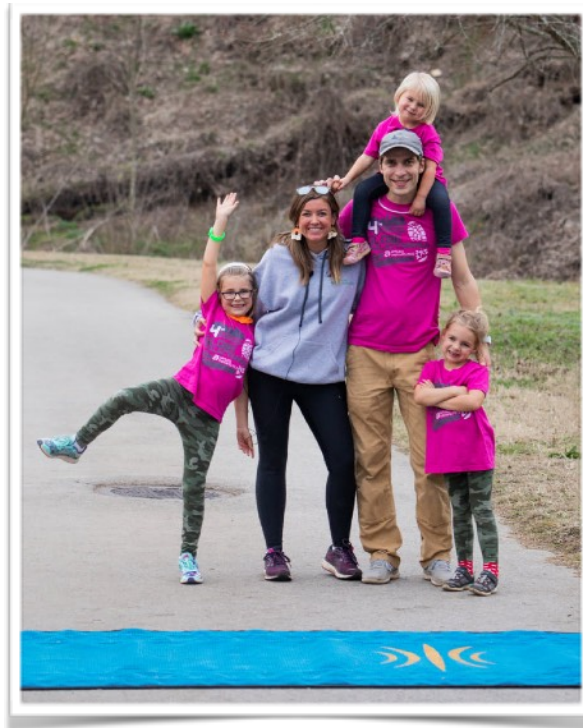
1. **WHAT ARE YOUR GOALS IN SHARING?** Summarize in one sentence your goal/objective in sharing your story. The most important thing to start with is, why do you want to share this?

2. **WHAT IS YOUR "HOOK"?** Should only be about 15 seconds long and should include a solid intro to who you are and what impact you seek to make

3. **BACK UP YOUR HOOK-** Here you give some specifics to add meat to your hook. You can give specifics from your story, what you are hoping for the future, how others can get involved.

4. **THE ASK:** Here, in the last 20-ish seconds, you have a call to action, that should directly correlated to your goals of sharing.

(If you can share a photo or a video, I believe that ALWAYS helps!)



How should you share?

1. *Social media-*

Social media is a great outlet to share your story to a broad audience, and in a variety of ways. You can reach family, friends, and bring in others to hear and connect with your story. Social media can be used in just about every goal of telling your story, or in broader goals, because you can continue to build on what you share and how you share it. In this context, the elevator speech is good because it can be repeated in different ways, and built on through different posts. People do listen to sound bits more than long involved stories- so 2 minutes is still a good fit.

2. *In rare disease or special needs groups, online or in person*

Finding others who are similar to you and sharing your story to connect with them is great to do in smaller groups. This is a more interactive and personal way to share and connect. Starting with a 2 minute intro is great, and then building more relationships from there.

3. *Join a foundation or group whose message resonates and connects to your story*

If your goal is to raise awareness in a bigger context, such as in policy, then connecting to foundations (such as the EveryLife foundation), advocacy groups (such as Haystack Project), and other groups (such as Global Genes) is a great way to add your voice to many others and make a bigger impact. Many times these groups will encourage action steps such as signing petitions and reaching out to congressmen about certain issues. The elevator speech is very important here

because you usually only have a couple minutes to make a splash.

4. *Creating an event, or being part of an existing one*

Creating an event may have several goals, but depending on who you are talking to about your event, you may have a couple of elevator speeches. Remember, its always good to know your goal and your audience so that you can stick to that quick, effective delivery.



An example: My elevator speech for fundraising

My name is Brittany Cudzilo, and I am a mom to 4 girls, 2 of which have a rare disease called Galactosemia. Galactosemia is a disorder that only affects a few thousand people in the United States and my daughter Ansell has life long impacts that include speech apraxia, sensory processing disorder, muscle weakness, developmental and cognitive delays, and she may experience pre ovarian insufficiency in her pubescent years with a high likelihood of infertility. Because of the rarity of this disorder,

there is no government funding for research or outreach, leaving the burden of raising funds for a better understanding of the disease to the families the disease affects.

As parents, my husband and I struggle with meeting the daily needs of all of our children because taking care of Ansell takes extra time and care. When she is in sensory overload, our lives can shut down so that we can provide her with comfort and support. When we are in social settings, we don't know if she will be ok, or as she is talking if she will be understood. As she has started PreK, we've had to navigate her delays and assess her cognition, which has consistently been behind her peers approximately 9-12 months. We have worries about the future, for Ansell and for her sisters.

Because of all of this, and our deep love for Ansell and all those who share in her diagnosis, we are committed to fighting for answers and treatment. We would love for you to join us in our fight by helping us raise the funds necessary to find those answers, and provide a brighter future for our girls.

An example of my elevator speech for FDA and policy

My name is Brittany Cudzilo, and I am a mom to 4 girls, 2 of which have a rare disease called Galactosemia. Galactosemia is a disorder that only affects a few thousand people in the United States and my daughter Ansell has life long impacts that include speech apraxia, sensory processing disorder, muscle weakness, developmental and cognitive delays, and she may experience pre ovarian insufficiency in her pubescent years with a high likelihood of infertility. Because of these affects, we made the weighted decision to enroll Ansell in the clinical

trial sponsored by Applied Therapeutics and their treatment with the drug AT-007.

As Ansell has been in the trial, we have seen incredible results. The trial is a blind study, so we cannot say with certainty that she is on AT-007, but what we can say is that we have seen life altering, significant changes since her last dose escalation which was 6 months ago. Ansell's speech is clearer with more complex sentences, she has memory that she has never had before, she is making huge gains in academics with her letters, shapes, and understanding of PreK concepts, she is sleeping better, and she is understanding more about the world around her. Although the study has been hard on her with the demands of blood draws, testing, and life disruptions, we have been amazed at her progression and are so thankful for the opportunity to be a part of this trial.

We believe, based on the reduction of the biomarker galactitol in the AT-007 data and the safety of the drug that this trial should be accepted on the accelerated approval pathway for FDA approval. We are committed to continuing the study for long term outcomes, but believe the drug should be available for others outside the trial (including our other daughter Louise).

We ask that you partner with us in our hope for AT007 to get into the hands of our community, so that gains like those that Ansell has experienced can be a possibility for others with Galactosemia. Every day that passes is another day of worsening affects, and we believe this drug can change lives.