



# USING STORYTELLING TO RAISE AWARENESS FOR YOUR RARE DISEASE

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## Introduction

Learning that you or a loved one has a rare or undiagnosed condition can be scary, confusing, isolating, and often forever life-altering.

“Where should I begin? How do I communicate what is going on with my friends, family, or healthcare providers?”

Many within the rare disease community do not know how great an impact they can have by sharing their story. Telling your story can be difficult, but this toolkit is intended to help you overcome the challenges by offering advice on ways to get started.

# SECTION 1:

## WHY RARE DISEASE STORIES MATTER



Sharing a rare disease story may feel like one more thing to worry about on a growing task list for managing a rare disease. While it's common for novice and even experienced storytellers to have doubts about sharing a personal experience, this should not overshadow the importance of storytelling for the rare disease community.

### Why Bother Telling Your Story?

Many people within the rare disease community have searched long and hard for a story that resembles their own, but with little success. The isolated nature of many rare diseases makes it essential to speak up. Your individual story could be invaluable to someone still searching. It's also an important way to raise awareness about a disease and can help researchers, doctors, and donors understand the human dimension of the work they do and support.

“My main reason for sharing comes from wishing when I was diagnosed that there had been someone like me out there, especially another young adult, blogging about their experiences,” says Erica Thiel, a blogger in the MPS1-HS patient community. (<http://www.rarelydefined.blogspot.de/>)

With the majority of healthcare professionals unfamiliar with identifying and treating patients with rare diseases, most patients and their

family members must rely on themselves or other patients and caregivers to learn about their own conditions.

For insights on the power stories hold and how one mother's story of her daughter's battle with Noonan Syndrome has led her on an unexpected path, read “**Our Stories Make a Difference: Rebecca with Noonan Syndrome**” on the RARE Daily (<http://globalgenes.org/raredaily/our-stories-do-make-a-difference-rebecca-with-noonan-syndrome/>). “There is power in our stories of our kids, adults, and families living with rare disorders,” she writes, “and through the written word, they teach, inspire, and raise awareness far beyond what we can ever imagine.”

### Benefits to the Community and to the Storyteller

By telling a story, you can help shed light on a condition's symptoms, prognosis, and other details for those still searching for the correct diagnosis or for someone who knows their disease firsthand. Medical terminology and data, though important, can obscure what it means to live with a disease and make it difficult for most people to relate. Personal stories, though, frame our individual rare experiences in a way that lets others connect.

“Storytelling gives data meaning,” says Sarah E. Kucharski @AfternoonNapper, writer and founder of FMD Chat, a Fibromuscular Dysplasia support organization. “Our stories are remembered because they help listeners to connect. To tell stories about our challenges and triumphs in coping with a diagnosis is simply an extension of connecting with one another.”

## SECTION 1: WHY RARE DISEASE STORIES MATTER

Finding common experience can break down feelings of isolation and build supportive networks. Outside the benefits to the larger rare disease community, you may also be able to save time and frustration by not having to continuously retell your medical history to others. To read more about obtaining and organizing your medical records, turn to the **Becoming an Empowered Patient: A Toolkit for the Undiagnosed** (<http://globalgenes.org/toolkits>).

By taking time to prepare your story before sharing it with others, you can take control over the story you choose to communicate. Creating a story may also provide an opportunity to develop stronger communication skills.

Capturing our stories gives us a chance to reflect and process what we've gone through. We reclaim lost memories, create new meaning around the journey, and take ownership over our medical files. Many storytellers in the rare disease community have found the process promotes healing. Fashioning a story establishes a valuable record for you, your family, and the greater community.

*"I have found it cathartic and healing to recount my journey as a caregiver/parent going through the death of my two sons and now my daughter's rare disease [a rare neuroendocrine tumor and genetic mutation]," says Jackie Barreau, Author of *Through A Mother's Eyes* (<http://www.jackiebarreau.com/>).*

### The Rising Increase in Storytelling Opportunities

Where in the past it was extremely difficult to establish connections between patients (even within the same specific disease group or region), the Internet has changed that. It is

fostering collaborations across borders and diseases. With many organizations working to improve patient access to information, storytelling opportunities continue to emerge. This is allowing patients to share insights, learn from each other, and work together.

The introduction of **Rare Disease Day** in 2008 marked a significant development in the growing strength of the rare disease community's voice. The annual selection of a theme for the day provides a rallying point for patients to join together. The recent addition of an official video helps unify the message, while at the same time, encourages individual stories to emerge. Online patient support communities, including **Ben's Friends** (<http://www.bensfriends.org/>), **Inspire** (<https://www.inspire.com/>), **PatientsLikeMe** (<http://www.patientslikeme.com/>), and **RareConnect** (<https://www.rareconnect.org/en>), are expanding the areas for linking patients through their stories.

We are also seeing the establishment of online news outlets, like the **RARE Daily** (<http://globalgenes.org/raredaily/>) and **Rare Disease Report** (<http://www.raredr.com/>), which are produced specifically for a rare disease audience and cover the latest rare disease stories. The growing movement towards patient-centered care, with an emphasis on the patient voice, is resulting in the inclusion of presentations from patients and caregivers at medical conferences and during regulatory drug reviews.

Self-publishing options and new communications technologies, especially smartphones and tablets, also make it easier to create and communicate a media message. Having a story ready-to-go allows you to respond to the opportunities that arise, such as an expedited drug review, a call for funding proposals, or to set the record

## SECTION 1: WHY RARE DISEASE STORIES MATTER

straight when public misrepresentations of a disease experience occur. Julie Flygare, founder and president of **Project Sleep** (<http://project-sleep.com/>), knows this all too well. After Honda featured a negative stereotype of Narcolepsy in one of its commercials, Flygare started a **Change.org** petition urging the automaker to pull the ad.

“There are times when your disease or condition may be painted in a light that is offensive or inaccurate in the media or pop culture,” says Julie Flygare, JD, president and founder of Project Sleep and Narcolepsy patient advocate. “While you can try to fight each misrepresentation on their websites through comments or sending emails, they may not be answered. It can be very powerful to return to your own site where you are not on the defense, but on the offense, sharing your story from a place of confidence and positive energy—as opposed to reacting in a state of negativity.”

Having that story in your back pocket is one of the critical tools for becoming an empowered patient advocate. See the **Appendix** to this Toolkit for more advice and resources from Julie Flygare.

## SECTION 2: GETTING STARTED



Writing a personal story can be exciting, scary, cathartic, emotional, simple, or extremely difficult. If you find yourself pushed into storytelling action while looking for answers, or drawing attention to an awareness campaign, read on for advice on how to get started.

### Setting an Intention

“So what?” That’s the first question many people ask themselves when it comes to working on a story. What’s the point? What will it accomplish? Before telling a story, consider why you are interested in sharing it. Is it to:

- Change an opinion?
- Have the reader relate to you?
- Spread awareness?
- Urge others to take action?
- Compare two things?
- Inspire an emotional reaction, indignation, or gratitude?

Keep your intention in mind as you begin to collect information, statistics, and anecdotes to weave into your piece.

“We receive dozens of patient stories each week at The RARE Daily,” says Ilana Jacqueline, managing editor of Global Genes’ RARE Daily. “For many patients, simply sharing their experiences brings relief and satisfaction to them. They hope their stories will help readers understand what living with this disease is like. Other writers want to provide resources and advice to readers.”

To submit your story to Global Genes, fill out the form ([http://globalgenes.org/patient\\_story\\_submission\\_form/](http://globalgenes.org/patient_story_submission_form/)).

When preparing a story, it is important to know who your audience is. If you identified your intention as spreading awareness about your rare disease to spur readers to take action and sign a petition, for example, your tone and content should reflect that.

If you are telling a story to your family or friends, you may want to keep your life as the focal point. But if you are telling a story to a national audience, make sure to identify shared patient/community concerns. For example, include some key statistics and facts that demonstrate the broader impact of rare diseases on patients across the country or globally; discuss the current lack of available therapies and treatments; etc. Then use your personal story to help illustrate these points and bring them to life. To find rare disease statistics and facts, go to the **Global Genes** website (<http://globalgenes.org/rare-diseases-facts-statistics/>).

### Picking a Storytelling Method

In the rare disease community, not so long ago, patient meetings were one of the few places to informally swap anecdotes. Captured stories were mainly limited to printed written material, such as organizational newsletters and disease information brochures. It was difficult for a true diversity of experiences to be properly represented, and the stories available were often one-off presentations or stagnant pieces that could not be updated.

While the written word continues to be a vital tool for storytelling, online distribution has grown in popularity. Web-based magazines, newspapers, journals, and ebooks are widely accessed, and new formats for sharing stories are also available, including blogs, YouTube, Facebook, and even Twitter.

## SECTION 2: GETTING STARTED







Storytellers in the rare disease community are taking advantage of a variety of creative methods, often in combination, to communicate personalized messages to both broad and specific audiences. A written story is likely what comes to mind first, but audiences have come to expect stories to draw our attention using video, photography, and audio recording to name just a few methods.

After setting an intention for your story, be sure to consider the most appropriate method at

your disposal. If you are unsure which method is right for you, ask yourself the following:

- Is there a method that is particularly relevant to my selected audience?
- What method am I comfortable using and enjoy working with, even if it hasn't been specifically for telling a rare disease story?
- Is there a method that's new to me that could be effective that I could experiment using?

Examples of different storytelling methods are showcased in the chart below:

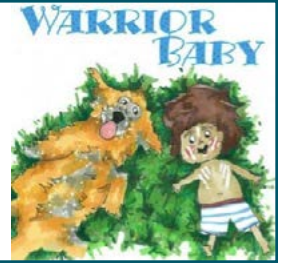
 <p><b>AUTOBIOGRAPHY</b></p>	<p><i>In Brain on Fire: My Month of Madness</i>, journalist Susannah Cahalan (<a href="http://www.susannahcahalan.com/">http://www.susannahcahalan.com/</a>) investigates and reports on her experience with anti-NMDA receptor encephalitis.</p>	 <p><b>BRAIN ON FIRE</b></p>
 <p><b>PUBLIC SERVICE ANNOUNCEMENT</b></p>	<p>Project Sleep founder and president, Julie Flygare, sets the record straight on narcolepsy by appearing in a PSA (<a href="https://www.youtube.com/watch?v=Us6vIX3HY2E">https://www.youtube.com/watch?v=Us6vIX3HY2E</a>) about sleep disorders sponsored by Honda.</p>	 <p>Julie Flygare Narcolepsy Spokesperson <a href="http://project-sleep.com">http://project-sleep.com</a></p>
 <p><b>PHOTOGRAPHY</b></p>	<p>An annual photo contest (<a href="http://www.eurordis.org/photo-contest">http://www.eurordis.org/photo-contest</a>) sponsored by EURORDIS, brings faces to rare disease stories.</p> <p>Lily and Tristan, twins in France living with mitochondrial cardiomyopathy with a mutation on the MRPL3 gene.</p>	





### CHILDREN'S STORYBOOK

Shannon Laffoon remembers and shares, though stories (<http://shoptogive.wylderjames.com>), life lessons from her son Wylder James, who battled Niemann-Pick type A.



### VIDEO DOCUMENTATION

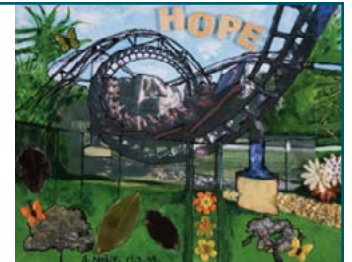
Christine McSherry, parent and executive director of The Jett Foundation for Duchenne Muscular Dystrophy, advocates shooting home video (<https://www.youtube.com/watch?v=CIC7PgsN0K8>) to show drug regulators how a treatment is impacting your quality of life.



### WORKS OF ART

The lysosomal storage disorders community raises awareness and inspires patients through the Expression of Hope gallery (<http://expressionofhope.com>) sponsored by Genzyme Corporation.

Artist: S. Noble, Mucopolidosis type 3 community



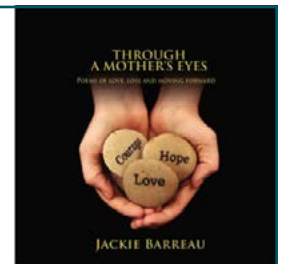
### DOCUMENTARY

To raise PKU awareness, professional videographer Kevin Alexander decided to put himself on the other side of the camera, filming "My PKU Life" (<http://www.pkulife.tv/>).



### POETRY

In Through a Mother's Eyes (<http://www.jackiebarreau.com>), author Jackie Barreau expresses her despair and hope, dealing first with the loss of two sons and later her daughter's rare disease diagnosis.



### DIGITAL STORY

Emma's Garden: Growing with Gaucher Disease weaves together illustrations, photos, home video, and a narrative voice to relate (<http://www.mynormal.ca/p/emmas-story.html>) a family's global journey.





## SECTION 2: GETTING STARTED

### Researching Background Information

Even though the story you'll be preparing draws from your own experience, you'll likely still need to devote time to research. During the research phase, there are a few things you may want to consider:

- Try picturing yourself as a journalist with a new story assignment on an unfamiliar topic
- Conduct an Internet search to see what's being said about the disease
- Identify key sources of available information, including experts in the field and leading organizations
- Note the hot topics and the significant developments being covered and also what's not being covered
- Look for medical information that accurately and easily explains the disease
- Make a list of key medical terms and definitions that may need to be included in your story
- Try to access medical files to review your own health history
- Interview family members, caregivers, and/or the health team to get their perspective and shed light on the pieces of your experience you have difficulty remembering
- Look through your personal belongings, such as photos, family videos, and old journals for useful clues

To organize your research, it can be helpful to use the information gathered to create a timeline of important events. Be sure to note your sources as you collect your research, and for the different pieces, identify if it's a fact, a memory, or an emotional response to an event. Nothing needs be discredited during the research phase, but separating these different pieces out can help you see what's going on, so you can be selective later when building your story.

# SECTION 3:

## PUTTING TOGETHER THE STORY



Each of us has a story to tell, often many. We can draw from the past, from what we're going through currently, and what we hope for tomorrow. The question is, what story do you want to tell today?

### Story Ideas

With your story intention in mind, start jotting down story ideas that could answer this intention. If you're stuck, visit a rare disease story source, such as **RARE Daily** (<http://globalgenes.org/raredaily/>), to get a feel for different types of rare disease stories. You can also review a list of story ideas below.

After identifying a few potential stories, be sure to ask yourself:

*Why this particular story now? Which story feels most urgent for me to be telling? What story do I really want my audience to receive?*

Work on this story first. If it doesn't seem to be going where you had hoped, you have some back-ups to try, including:

#### Advocacy:

- Advocating for access to trials/treatment
- Advocating for my child at school
- Becoming a rare disease advocate
- How I raised awareness
- Leadership in the rare disease community
- Not being able to afford the healthcare I need
- Speaking up: why I decided to share my story
- The case for treatment: impact on my quality of life

- This needs to be changed now
- Using my skills to support the rare disease community

#### Diagnosis:

- Journey to a diagnosis
- My child is not their diagnosis
- My first response to the diagnosis
- My unsolved medical mystery
- What I wish I had known in the beginning

#### Knowledge, Experience, and Insight:

- Creating an accessible home environment
- Finding balance while living with a rare disease
- Knowing more than the experts
- Living my normal day-to-day
- Making my job work for me
- Rare disease through a child's eyes
- Researching my disease
- Taking control of my medical file
- Traveling with a rare disease

#### Medical Care:

- A trip to the hospital
- Finding a doctor who knows about the disease
- How a scientific advancement changed my life
- Learning how to communicate with the health team
- Medical care beyond drugs
- On the road to recovery
- Participating in a clinical trial
- Receiving care at home
- Starting treatment
- There's more to my health than my rare disease

#### Support:

- Finding someone like me
- My rare disease hero
- Supports that make the world of difference
- Telling my family and friends I have a rare disease
- What it's like to be a caregiver
- Why I joined a support community

## SECTION 3: PUTTING TOGETHER THE STORY

### Deciding What to Include

There are many reasons to share a story. Some patients share their story because it is unfinished. They want to reach out to others for help and guidance, while others may not come in with a plan. They want to tell their story, but they don't know what they can offer—or what they're looking to receive. When a story seems to lack direction, here are some questions that might help:

**Are there challenges presented in your story to which others may relate?** This could include the long journey to receive a diagnosis, access to care, or finding others who have gone through a similar experience.

**What actions have you taken, or wish you had taken, to positively affect your journey?** This can show others what they may be able to do if they are in a similar situation.

**How is your day-to-day health impacted by your rare disease? What kind of symptoms do/did you experience?** This can help the audience make a connection to a similar diagnosis or condition.

**What part of your story helps guide the audience forward?** Leaving people with something specific to do empowers them to get engaged and be part of the story.

Remember that sometimes it is hard to decide what not to include. If a story is starting to become too lengthy, revisit what its original focus and purpose was, and try to edit it down so it is a more manageable size. A good rule of thumb for online written stories would be between 550-750 words.

### Reviewing the Story and Getting Feedback

Always take the time to step away from the story and come back to it later, re-energized, and with fresh eyes. Try to step into the shoes of the audience as you look it over. What parts of the story seem unclear or confusing? Is there necessary context information? Pay extra attention to how it begins and ends. Make sure that the beginning sets the right tone and direction, while the conclusion leaves a lasting impression. Endings are often unpolished because the storyteller is rushed. It is worthwhile to go back and make final improvements. Also, think about the title. Does it draw attention to the story while also offering a clear indication of what it is about?

Once you've developed the story as much as you can on your own, it can be helpful to ask someone you trust, who isn't emotionally invested in the story, to review it. Many people are pleased to be asked to do so and will happily take the time to share their thoughts. When requesting feedback, try to be clear about the type of input you're looking for. Getting someone's general impression is always useful, but asking for specific ideas on how to strengthen it can be fruitful. It can require a different set of eyes to catch spelling and grammatical errors versus identifying parts that don't make sense or may seem dull. Also, if medical information is included in the story, consider approaching someone with a medical background to review the content for accuracy. Remember, always fact check to ensure your story is credible.

Being receptive to any advice you receive doesn't mean you have to accept all of it. Consider where your reviewer is coming from and how their feedback fits with what you're trying to accomplish with the story. Remember, always fact check to ensure your story is credible.

## SECTION 3: PUTTING TOGETHER THE STORY



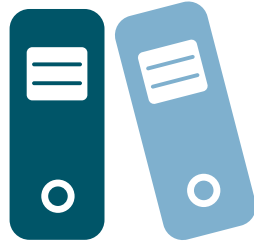
### Protect Your Privacy! Protect Yourself!

Only you can decide what's most appropriate to share from your personal experience. A good story need not reveal personal information you're not comfortable providing. Take a bit of time to reflect on the following questions before sharing your story:

- Where are you sharing this story, and what level of control will you have over how it's presented?
- Is it clear that the ideas expressed are your own? Are there ways they could be misinterpreted?
- What will be the life of the story? How long will it remain public and in what format? How will you feel about it tomorrow, next month, or beyond?
- If your intended audience were right now sitting directly in front of you, how comfortable would you feel sharing your story as it stands?
- Can telling this story negatively impact your future employment opportunities, access to healthcare, or important relationships?
- Who else has been mentioned in your story and how might they feel about seeing your representation? Have you considered the responses you may get from those closest to you?
- Have you mentioned specific products, institutions, or organizations? What might be the implications?
- How do you think you'll feel after sharing, and what support will you have in dealing with any emotions that may arise?
- Are you ready to receive feedback (positive or negative) on your story from strangers?
- Have you "slept" on your story before deciding you are comfortable to go ahead and share it?

"When others express a problem or issue which I have gone through, I am inspired to write a story about what I know," says Wendy Station, founder and president of Encephalitis Global (<http://www.encephalitisglobal.org/>). "I am always careful to commence my statements by saying, 'I am not a medical professional. I am an encephalitis survivor sharing information and support from my own personal experience'."

# APPENDIX: KNOWING WHERE TO BEGIN



Julie Flygare, Project Sleep

Rare disease storytelling is important because people remember stories and faces over medical terms and statistics. Facts are important, but to open people's hearts to your situation, it's essential to tell stories from the first-person and with details.

Consider the following:

"I was so tired I fell asleep on my bare mattress with my clean sheets laying folded at the bottom of the bed" or "I collapsed to the ground with my knees hitting the concrete floor as I fell."

These details allow your listener to create pictures in their minds, and they can envision the scratchy mattress against their skin and the cold hard concrete, and then they can begin to picture themselves in your shoes.

Everyone has a story to tell. You do not have to be a superwoman overcoming an illness with supernatural powers. You don't have to be a professional speaker. You can tear up, stumble through your words, and discuss your troubles. The raw moments are what touch people the most. You just have to have the courage to sit down in front of a camera and speak your truth, without knowing how many lives you are touching around the world. Your story matters and will help others find the proper diagnosis, support, and strength they'll need to face another day.

**"Begin Anywhere—Just Begin."**

Many people look to big media outlets like Marie Claire and Oprah in the hopes of getting their story picked up. Those outlets are great. They are the jackpot, and sometimes you can land something huge like this with luck. But the secret to long-term media success is in starting small, local, and with your current network. Reach out to your high school or college newsletters, your community newspapers, your local doctors groups, bloggers, friends, and contacts. Don't be afraid to ask someone for an informational interview. Ask them how they got started. Ask for advice. Build relationships by supporting someone's efforts for a while before asking for any favors.

You never know who your story will reach or when. I published a small article in my high school alumni online newsletter, not knowing that a year later, an old high school classmate of mine who worked for Marie Claire would take an interest in it. You never know. Just pursue every path, no matter how big or small the market/readership may seem. Many media projects fall through, but those that end in publication will help you establish your platform.

## APPENDIX: KNOWING WHERE TO BEGIN

Last but certainly not least, come up with an interesting angle, challenge, or story to grab the media's attention. Is there an awareness day or event coming up? Inform the media of this and how it relates to your story.

### Resource Tips from Julie

- For raising awareness through writing, I took creative non-fiction writing classes at a local writing center to help me improve my creative writing skills.
- For those interested in raising awareness through speaking or videos, I recommend **Toastmasters** (<http://www.toastmasters.org/>), where you can practice public speaking and get helpful feedback. This is a very safe space to share your story and improve your skills rapidly. I also love **fiverr.com**, a great site that can help patients and family members create some professional visual elements for your media efforts inexpensively.



# RESOURCE GUIDE



## Creating a Story with Media

- **Center for Digital Storytelling** (<http://storycenter.org/public-workshops/>): This organization offers a wide range of workshops to the general public for professional development opportunities.
- **Fiverr** (<https://www.fiverr.com/>): This global online marketplace offers tasks and services, allowing patients and family members to create professional elements for an affordable price.
- **TechSoup's Storymaker Resources** (<http://www.techsoup.org/community/community-initiatives/storymakers-resources>): TechSoup's digital storytelling resources provide a step-by-step guide from story creation through post-production and marketing.

## Getting Started

- **Changmakers' "A Changemaker's Guide to Storytelling"** (<https://www.changemakers.com/storytelling>): This resource details four key types of stories used to impact change and how social innovators can take advantage of storytelling.
- **CNN iReport Toolkit on Storytelling** (<http://ireport.cnn.com/toolkit.jspa>): This toolkit offers pieces of advice from CNN reporters on what makes a good news story.
- **Developing and Telling Your Personal Story Slides** (<http://www.mpssociety.ca/Vimizim%20Updates/Morquio%20IVA%20Webinar%201%20-%20Feb%2026%202014%20v2.pdf>): These webinar slides were presented by The Canadian MPS Society and covers useful tips on developing a personal story for advocacy.
- **FreeBookNotes' "Ultimate Guide to Storytelling"** (<http://www.freebooknotes.com/storytelling-guide/>): This collection of resources provides users with information on a myriad of storytelling subtopics.
- **My Normal's "10 Ideas for Getting Started on Your Story"** (<http://www.mynormal.ca/p/10-storytelling-starters.html>): This article includes tips for starting the storytelling process.
- **Patient Commando's "Writing a Patient Narrative"** (<http://patientcommando.com/resources/storytelling/>): This article offers a 12 step approach for creating a story.
- **Toastmasters** (<http://www.toastmasters.org/>): Toastmasters offers communication and leadership development. Members can improve their speaking, while in a supportive and positive environment, to feel prepared when putting together a story.

## Online Communities that Encourage Storytelling

- **Ben's Friends** (<http://www.bensfriends.org/>): This organization is a network of safe and supportive patient communities for anyone affected by a rare disease.
- **EURORDIS TV** (<http://www.eurordis.org/tv/>): This is the largest online catalogue of rare disease video stories divided into category channels. Users can easily tweet or email to request inclusion of a new video story.
- **Inspire** (<http://www.inspire.com/>): Inspire was created with the belief that patients and caregivers need a safe and secure place to support and connect with one another.

# RESOURCE GUIDE



- **Jeans for Genes** (<http://www.jeansforgenesday.org/howyourmoneyhelps/meetchildrenwehelp>): It can be difficult to imagine what life is like for a child with a genetic disorder. Here you can read stories from affected families who have benefited from monies raised on Jeans for Genes Day.
- **NORD, Patient Stories** (<https://www.rarediseases.org/patients-and-families/patient-stories>): This nonprofit organization is dedicated to helping people with rare “orphan” diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.
- **RareConnect** (<https://www.rareconnect.org/en>): This EURORDIS initiative, run with members of its Council of Rare Disease National Alliances, allows users to meet and interact with others who share their condition in a supportive and friendly environment. Find the information and support needed and share your own experiences.
- **Rare Disease Day** (<http://www.rarediseaseday.org/tell-your-story/>): Rare disease patients and family members from all over the world participate in Rare Disease Day, and many of these share their stories through the event’s website.
- **Rare Disease UK** (<http://www.raredisease.org.uk/living-with-a-rare-disease.htm>): This organization works to raise awareness of rare diseases and the impact that they have on those affected by them. This section of the website provides an insight into the experiences of people living with rare diseases and allows others to share their story.
- **RARE LIVES** (<http://www.rarelives.com/>): RARE LIVES is a photographic journey across Europe with the aim to investigate needs, hopes, difficulties, but, above all, joys and daily achievements of those living a “rare life.”
- **Rare Voices Australia** (<https://www.rarevoices.org.au/page/14/living-with-a-rare-disease>): This national organization advocates for those who live with a rare disease. Rare Voices provides a strong common voice to promote for health policy and a healthcare system that works for those with rare diseases. It also has a collection of patient stories that allows the visitor learn about what it is like to live with, or care for, someone with a rare disease. Rare Voices encourages others to contribute their stories.
- **The Translational Genomics Research Institute’s Dorrance Center for Rare Childhood Disorders** (<http://www.c4rcd.org/every-child-matters.aspx>): Rather than fighting one specific disease, the Dorrance Center for Rare Childhood Disorders (C4RCD) rallies around each child, joining with loved ones, medical staff, researchers and the larger scientific community to find the genomic causes and new treatments for a broad spectrum of illnesses. The center also encourages bringing patients and their families together to share their stories.

## Online News Outlets

- **RARE Daily** (<http://globalgenes.org/RAREDaily>): The RARE Daily is a reader-friendly, online news magazine and source for the latest information in the rare disease community.

# RESOURCE GUIDE



- **Rare Disease Report** (<http://www.raredr.com/>): Rare Disease Report is a website and weekly e-newsletter that offers an independent voice for the rare disease community. It strives to bring together medical, scientific, investment, regulatory, and advocate professionals interested in rare diseases and orphan drugs.

## Storytelling Examples Referenced in Toolkit

- **Brain on Fire: My Month of Madness** (<http://www.susannahchalan.com/>): Journalist, Susannah Chalan investigates and reports on her experience with anti-NMDA receptor encephalitis in this autobiography.
- **Emma's Garden: Growing with Gaucher Disease** (<http://www.mynormal.ca/p/emmas-story.html>): This digital story weaves together illustrations, photos, home video, and a narrative voice to relate a family's global journey.
- **EURORDIS Photo Contest** (<http://www.eurordis.org/photo-contest>): This photo contest brings faces to rare disease stories.
- **Expression of Hope Gallery** (<http://expressionofhope.com>): Sponsored by Genzyme Corporation, this collection of works of art for the lysosomal storage disorders community raises awareness and inspiration.
- **"How to Talk to the FDA" Video Documentation** (<https://www.youtube.com/watch?v=CIC7PgsN0K8>): Christine McSherry, parent and executive director of Jett Foundation for Duchenne Muscular Dystrophy, advocates shooting home video to show drug regulators how a treatment is impacting your quality of life.
- **My PKU Life** (<http://pkulife.tv>): Professional videographer, Kevin Alexander, decided to put himself on the other side of the camera in this documentary.
- **Narcolepsy Public Service Announcement** (<https://www.youtube.com/watch?v=Us6vIX3HY2E>): Project Sleep founder and president Julie Flygare sets the record straight on narcolepsy by appearing in a PSA about sleep disorders, sponsored by Honda.
- **RARE Daily's "Our Stories Make a Difference: Rebecca with Noonan Syndrome"** (<http://globalgenes.org/raredaily/our-stories-do-make-a-difference-rebecca-with-noonan-syndrome>): In this piece, the writer shows the power stories can have and how her experience as a mother with a story has set her down an amazing path.
- **Through a Mother's Eyes** (<http://www.jackiebarreau.com>): Through this collection of poetry and images, author Jackie Barreau reflects on grief, loss, and love.
- **Warrior Baby** (<http://shoptogive.wylderjames.com>): Shannon Laffoon remembers and shares through a children's storybook the life lessons from her son Wylder James, who battled Niemann-Pick type A.



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