



DECEMBER 2022

Caring for Yourself and Your Children



About **Global Genes**®

Global Genes is a 501(c)(3) non-profit organization dedicated to eliminating the burdens and challenges of rare diseases for patients and families globally. In pursuit of our mission we connect, empower, and inspire the rare disease community to stand up, stand out, and become more effective on their own behalf—helping to spur innovation, meet essential needs, build capacity and knowledge, and drive progress within and across rare diseases. We serve the more than 400 million people around the globe and nearly 1 in 10 Americans affected by rare diseases. If you or someone you care about has a rare disease or is searching for a diagnosis, you can *contact us by submitting our confidential form*. A Patient Services Guide will provide you with a personalized response within 2-3 business days that will include information, resources, and connections that address your specific needs.

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Introduction

Living with a rare disease is like running uphill over one hurdle after another. Fatigue and pain come with the territory. On top of that, there's the extraordinary effort needed to manage your health, pay your bills, hold down a job, and face the problems and hassles of modern life.

These energy-sapping challenges, however, are the least of the worries for rare disease patients with children. Because every day, their main focus is summoning the strength, perseverance, and empathy to help their children cope with the uncertainties, grief, sadness, anger, despair, and fears precipitated by the disease.

Fortunately, we have many amazing people in our community who can guide and inspire parents with rare diseases to overcome these obstacles and live their best lives. People such as:

Adam Johnson, a rare disease patient and "DadVocate" with a young daughter and son who, at the age of 35, was diagnosed in 2019 with mitochondrial myopathy. Adam writes a *Rare Disease Dad* blog, hosts a podcast series called Parents as Rare, and runs a support group for men with mitochondrial disease.

Robin Powers, who was diagnosed with Ehlers-Danlos syndrome before the birth of her son, who also has a rare disease. She is a single mom who has worked with EveryLife Foundation to help shape public policy on Capitol Hill and is an Ambassador for the Patient-Centered Outcomes Research Institute.

Mary Morlino, the RARE Concierge Patient Services Manager at Global Genes who was diagnosed with multi-system sarcoidosis when her two children were teenagers. She is the co-founder of MarylandRARE, a patient-led coalition that focuses on legislative policies, and works with the Foundation for Sarcoidosis Research.

Deborah Vick, who was diagnosed with the first of her two rare diseases when she was 25 years old and is mom to two teenage boys. She is the CEO and co-founder of the non-profit VICKtorious, which helps women who feel marginalized pursue leadership roles through the power of their voices, and Ms. Wheelchair California USA. Her experiences have inspired her to raise awareness of the needs of people battling chronic illnesses and chronic pain.

These individuals shared their experiences in a “Parenting while RARE” session at the recent Global Genes Patient Advocacy Summit, which is the primary source for most of the information in this toolkit. Since self-care is essential for parenting, the toolkit also includes a section on where to find resources to help lighten the load of everyday living.

Although the life journeys for each rare parent and child are unique, we hope you will be inspired and comforted by the stories and insights of Adam, Mary, Robin, and Deborah, whose admirable lives exemplify the meaning of compassion, grit, and grace. And remember, Global Genes is always here to help you in any way we can. To contact us, [fill out our confidential Patient Services form](#). Within 2-3 business days, you will receive a personalized response that will include information, resources and connections that address your specific needs.

Rare Reminder: You Are Not Alone

The initial reaction to learning you have a rare disease often is some combination of relief and utter confusion. There’s some solace, of course, in knowing that the cause of your problems has a name.



RARE TIP

“When I got my diagnosis I thought I was the only parent out there with a rare disease. And when my doctor told me it was progressive with no treatment and no cure, and good luck with all that, I felt like the John Travolta confusion meme from Pulp Fiction, where he’s turning in circles with a look that says, ‘where is everybody?’”

Robin says that for her it was like “being on a boat in an ocean with nobody else around me.”

Adam, Robin, and countless others on the front lines of rare disease advocacy are dedicated to ensuring that rare disease patients no longer feel so lost and abandoned. As Deborah reminds us, “We can all help each other by sharing what we’ve learned and found helpful in trying to live our best lives. We all have a voice to let people know, ‘You’re not in the ocean by yourself.’”

Caring for Yourself

Let's face it – good parents will always put their children's needs ahead of their own. But it's likewise true that when you're so run down and frazzled that you can't even think, you're in no condition to care for anyone else. By taking better care of yourself, you will not only be a better parent but also a better partner, friend, and co-worker. Finding the right balance between self-care and self-sacrifice can be tricky, and you might find it reassuring to know that no one gets it right every time. Here are some ideas and tips to give yourself the attention and care you need to be a better (and healthier) person and parent.



RARE TIP

“Do not confuse self-comfort with self-care. Drinking lots of hot cocoa and watching Netflix may be self-comfort. Exercise or mindfulness may be self-care.”

-JESSICA PATAY, FOUNDER OF WE ARE BRAVE TOGETHER

Know What's Most Important to You

Self-awareness is the foundation for self-care. Start by asking yourself, what's most important to me as a person and parent? For example, your priorities might include:

- Maintaining a high quality of life
- Reducing the stresses caused by your illness
- Finding support for you and your children
- Staying positive about life
- Modeling the attitudes and behaviors you would want your children to emulate
- Having the peace of mind knowing your children will be cared for when you can no longer do this

“After I had a son, I realized I had to survive, which meant I had to be selfish. That was hard, but if I don't help myself first I can't help other people.”

- ROBIN POWERS



RARE TIP

Be Thoughtful in How You Spend Your Energy and Time

“I’m selective about where I put my energy and also pay attention to what gives me energy. When you have a rare disease you lose a lot of your power. Participating in this Global Genes advocacy summit and the work I do on RARE Concierge helps me feel more empowered because I can use my passion and energy for something I care about that gives me purpose. I also try to conserve my energy by eliminating the little things in life not worth of the worry.”

As wellness expert [Joyce Sunada](#) notes, “If you do not make time for your wellness, you will be forced to take time for your illness.”

Create Your Own Support Team

Realize that there are no superheroes in rare disease caregiving – at some time, everyone needs help. Cristol Barrett O’Loughlin, the founder and CEO of [ANGEL AID](#), which provides mental health and wellness services to rare

families in 15 countries, recommends building a well-being team so that you can practice self-care. Team members could include a friend, neighbor, or someone from church to provide respite care and allow you to take some time for self-care practices (e.g., physical activity, journaling, yoga).

Be Organized and Prepared

When you have a rare disease, one thing is certain: You can expect the unexpected. To alleviate the anxiety of knowing that the next crisis could come at any time, make sure you and your children are as well-prepared as possible for any emergency. A good first step is to create a care notebook that includes:

- Your medical history, including doctors’ reports and test results
- A list of your medications
- A list of your hospitalizations
- Contact information for all of your healthcare providers and anyone on your care team
- Insurance information
- Other items in your daily care schedule
- The steps your child or children should follow in the event of various emergencies most likely to occur

Preparedness in Action

“Planning is essential. When my son found me unconscious one day, he and my daughter knew that I immediately needed my airway pressure ventilator to help me breathe. My kids check in everyday and say, ‘OK, Mom what do you need from us now?’”

– DEBORAH VICK



RARE TIP

“Being ready for any type of emergency and communicating to your children about your disease can be incredibly helpful in preparing them to handle all the things that will come their way.”

– MARY MORLINO

Learn more

For more information, care notebook templates and resources, check out the Global Genes’ toolkit, [Building a Care Notebook](#).

Caregiver Balance and Self-Care

Cristol Barrett O’Loughlin, Founder and CEO of Angel Aid, recommends the following series of steps to help you identify the support you need to continue caregiving— including the financial side of caregiving—in a sustainable way.

- Be forgiving of yourself. Acknowledge that caregiving is hard for everyone.
- Give yourself permission to seek support from others.
- Build your well-being team so that you can practice self-care.
- Team members could include a friend, neighbor, or someone from church to provide respite care and allow you to sit down for a couple of hours to pay bills, get into financial balance, or create space for self-care practices (e.g., physical activity, journaling, yoga).
- Financial experts, financial navigators, or health insurance financial advocates could also be members of your well-being team.
- Health insurance companies provide access to financial advocates in other mature disease states (e.g., breast cancer) to help navigate health insurance. Ask for the same service.
- Describe the impact of caring on your physical and mental health.
- Help the insurer understand that they need to support you so that you can continue to care for your child.

Learn more in [Global Genes’ Financial Literacy and Navigation toolkit](#).

Caring for Children

Being a child in these turbulent times is tough enough without the added hardships, stresses, and emotional tumult of having a parent with a rare disease. And having this kind of disease is tough enough without knowing that it will certainly have an adverse effect on your child or children. If you're like many rare disease parents, the guilt you feel about this can be worse than the disease's physical manifestations.

So let's make four things clear at the outset.

1. You didn't choose to have your disease and are not responsible for its effects.
2. Parenting in your condition is unbelievably hard.
3. You're not perfect, so you're going to make mistakes.
4. Forgiving yourself for causing your child pain and grief is one of the best things you can do for the both of you.

"I felt guilty because the disease meant our family couldn't live the life we expected to have. I've spent the majority of my time in bed and my children have PTSD from all my 'hospital vacations.'"

– DEBORAH VICK

"My kids were 15 and 17 when I was diagnosed and I felt guilty about how this would change their lives. But they were incredibly brave and reassured me that they were going to be OK."

– MARY MORLINO

Dealing with Emotions: Grief, Fear, and Coping Strategies

For rare disease parents and children, life can be an emotional roller-coaster. And each person experiences these ups and downs in unique ways. Sometimes, as [this story by Adam Johnson](#) shows, the ride can be simultaneously exhilarating and heartbreaking.

"My daughter came home from school and said, 'Dad we're doing this project in science where our teacher asked us to write about parts of the body. Since mitochondria wasn't on the list I asked if I could write about it.' My heart was simultaneously filling up and breaking into pieces."

"Although she had been reluctant to talk to me about my disease before then, I realized that she was now ready to have that conversation."

Clearly, it's important to pay close attention to these kinds of cues that children send out all the time to let us know what they are thinking, feeling, and wanting. For example, when Deborah's son asked his school to give him another year of virtual classes to protect her from Covid, she recognized that he was telling all of them that he was afraid.

For both parent and child, the grief of not being able to have a so-called "normal" life is real and raw. All four conference panelists acknowledge having experience with this. Robin commented that, "I was grieving for myself and a life I could no longer have and the fact that my son had to cope with having a sick mother."

It also can be especially beneficial for parents to be aware of their own feelings and express them appropriately to their children.

Helping Your Children Cope

"By acknowledging and showing that we too are sometimes sad and afraid, we validate what our kids are feeling and give them permission to continue finding their own way to cope and heal."

- ADAM JOHNSON

The Fear Factor: Two Stories

Seeing the fear in your child's eyes when you're having a traumatic event can be especially unnerving and terrifying. Here's how Mary Morlino describes her feelings and responses after collapsing in her kitchen from cardiac arrest in front of her 15 year-old daughter.

"Luckily, I had a pacemaker defibrillator and was able to make it to the hospital where I was hooked up to all these machines. My daughter was in the room with me and I was thinking, How is this going to traumatize her? I'm trying to be like 'everything's fine, everything's ok,' but at the same time I'm terrified for myself and my daughter and afraid of how she and my other child will cope with this. Although I tried to be as straightforward and calm as possible, I was also aware that our fears were real. It's awful to be in such a vulnerable situation where you want to protect your kid and know that you can't."

Robin and her young son had an experience similar to Mary's that eventually led to a roller-coaster of feelings comparable to Adam's.

"I've had two cardiac arrests in the last four years and my son witnessed one of them. Later, he was asked in school what his Mom wanted most, and he replied, 'to be healthy.' I couldn't help but cry so much when I heard that because he was the only person who's ever said that to me. But I also saw this as a sign that he was Ok, which I found very comforting."

7 Coping Strategies and Tips

- **Recognize and share the emotional commonalities between you and your child.** For example, feelings such as joy, grief, despair, hope, and even fear can be the impetus for making deeper connections and strengthening your relationships.
- **Embrace your role as a model for your children.** All four summit panelists epitomized the meaning of perseverance. Robin, for example, took more than 13 years to earn her degree in biochemical pharmacology at Buffalo State College in 2019, after passing her final exam despite vomiting several times because of her chemo treatments.
- **Set aside time and space for yourself.** Deborah, for example, has a mindfulness corner in her house where she meditates every day. During the worst days of the pandemic, she leaned into her mindfulness practice to deal with the stress of balancing changes in her disorder with her kids' and husband's needs.
- **Be calm and candid when talking about your disease and speak in terms they can understand.** As a noted playwright once said, 'the single biggest mistake in communication is the illusion that it has taken place.' Adam suggests using kid-friendly language and keeping things simple, open-ended, and as positive as possible. "After my diagnosis, I told my kids that Daddy is sick, and even though we finally have some answers, there's not a lot we can do. I'll need to rest a little more, and I have some tools that can help me do my best in dealing with this disease."
- **Be honest with yourself and family about what you can and cannot do.** And ask for help when needed – this can also make your kids feel better because they're not just helpless bystanders but are doing something that can make your life a little easier.
- **Celebrate your accomplishments.** As Adam remarked, "I'm proud to be a speaker at the Patient Advocacy Summit. It feels good to show my kids that I can still do things and make a difference."
- **Laugh and love.**



RARE TIP

“My kids have seen me in a wheelchair for their entire lives and watched me get progressively worse. All this time, sarcasm and humor have been our coping mechanism. Laughter is healing. It allows us to address serious issues in a light manner and to connect with what’s happening without the experience dragging us down.”

“The best advice I can give is to not try to do everything and be everything to everyone. Even if we didn’t have disabilities and challenges, it’s unrealistic to think that anyone could do this.”

– DEBORAH VICK

On the Bright Side

Despite having to navigate an endless gauntlet of trials and tribulations, the conference summit panelists have somehow found a way to stay positive, at least for some of the time. Obviously, their roles as advocates, speakers, and educators in the rare disease community have given them a rewarding sense of purpose and

self-worth. But, despite the bad cards life has dealt them, they also seem intrinsically optimistic. As Robin notes, “The odds of us being born are astronomical, so we are blessed just to be alive. Why not try to enjoy every minute.”

They also see a silver lining in the hardships and trauma their children have had to endure. Deborah notes that, “my children are more compassionate and empathetic in ways they wouldn’t have been if I hadn’t had this rare disease.” Adds Mary, “empathy and understanding and adaptability have become part of who my children are. As they go out into the world, they are bringing some amazing life skills into other aspects of their lives.”

Deborah’s view of how she and her family deal with her disease describes a mindset that others with rare diseases might consider adopting in their self-care and parenting efforts.

“Even though I’ve had more near-death experiences than I’d like to count, we can’t spend all our time worrying about what could happen. Let’s just live now knowing that we’ve done the best we can for ourselves, our friends and our families.”

Resources for Everyday Living

Managing your health and finances. Coordinating your care. Getting the right insurance and benefits you deserve. Scheduling appointments. Finding employment. Advancing your career.

The time you spend trying to juggle and address the constant demands of everyday living drain your energy and make it extraordinarily difficult to care for yourself, let alone your children. Here are some resources to check out that could help make your life a little easier.

Global Gene Toolkits

How to Access and Maintain Social Security Benefits

Navigating Health Insurance

Financial Literacy and Navigation in Rare Diseases

Understanding Career Opportunities and Employment Benefits

Building a Care Notebook

Other Resources

Patient Advocate Foundation

Rare Disease Patient Organizations

Rare Disease Job Search

Hope. It's in our genes.



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