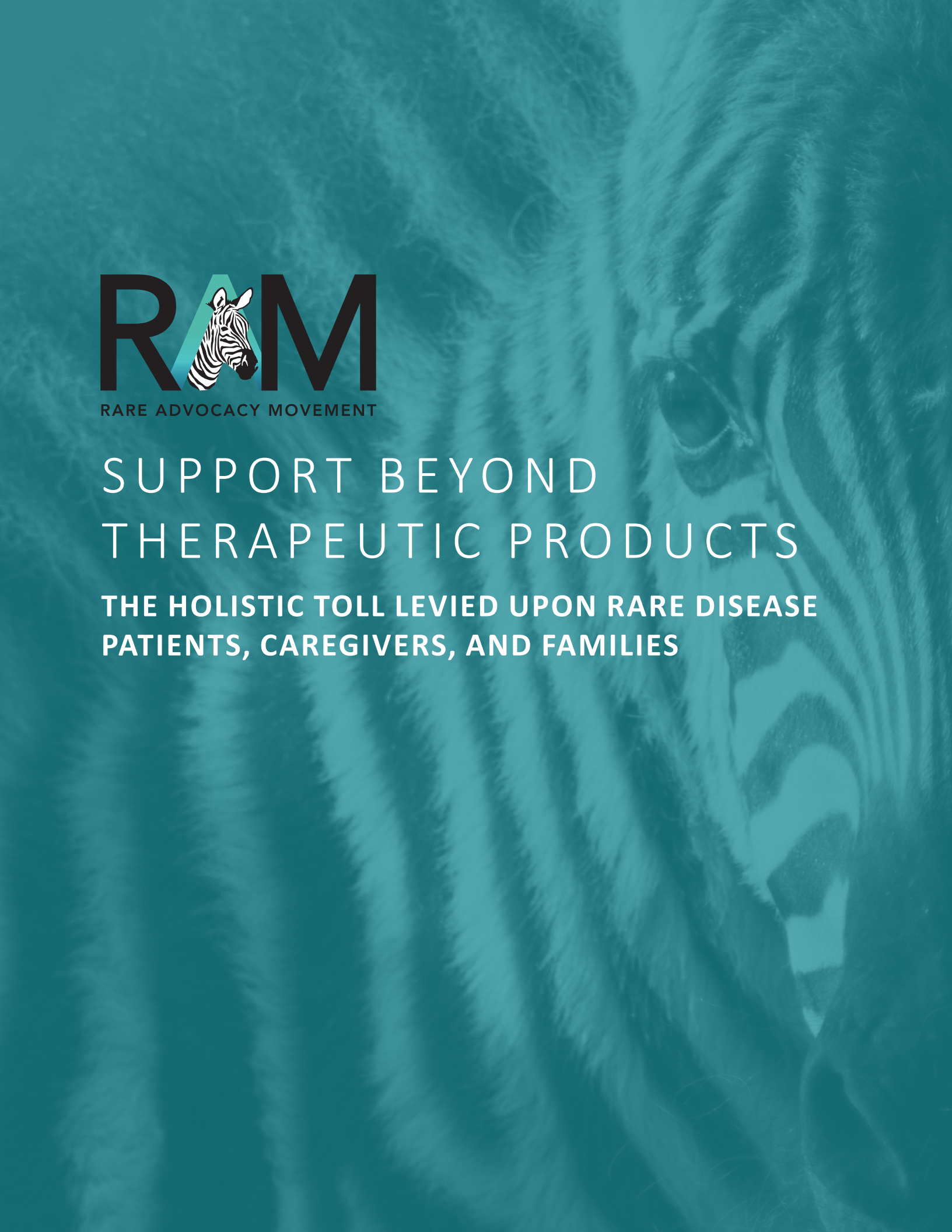

RARE ADVOCACY MOVEMENT

SUPPORT BEYOND THERAPEUTIC PRODUCTS

THE HOLISTIC TOLL LEVIED UPON RARE DISEASE PATIENTS, CAREGIVERS, AND FAMILIES

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THE HOLISTIC TOLL LEVIED UPON RARE DISEASE PATIENTS, CAREGIVERS, AND FAMILIES

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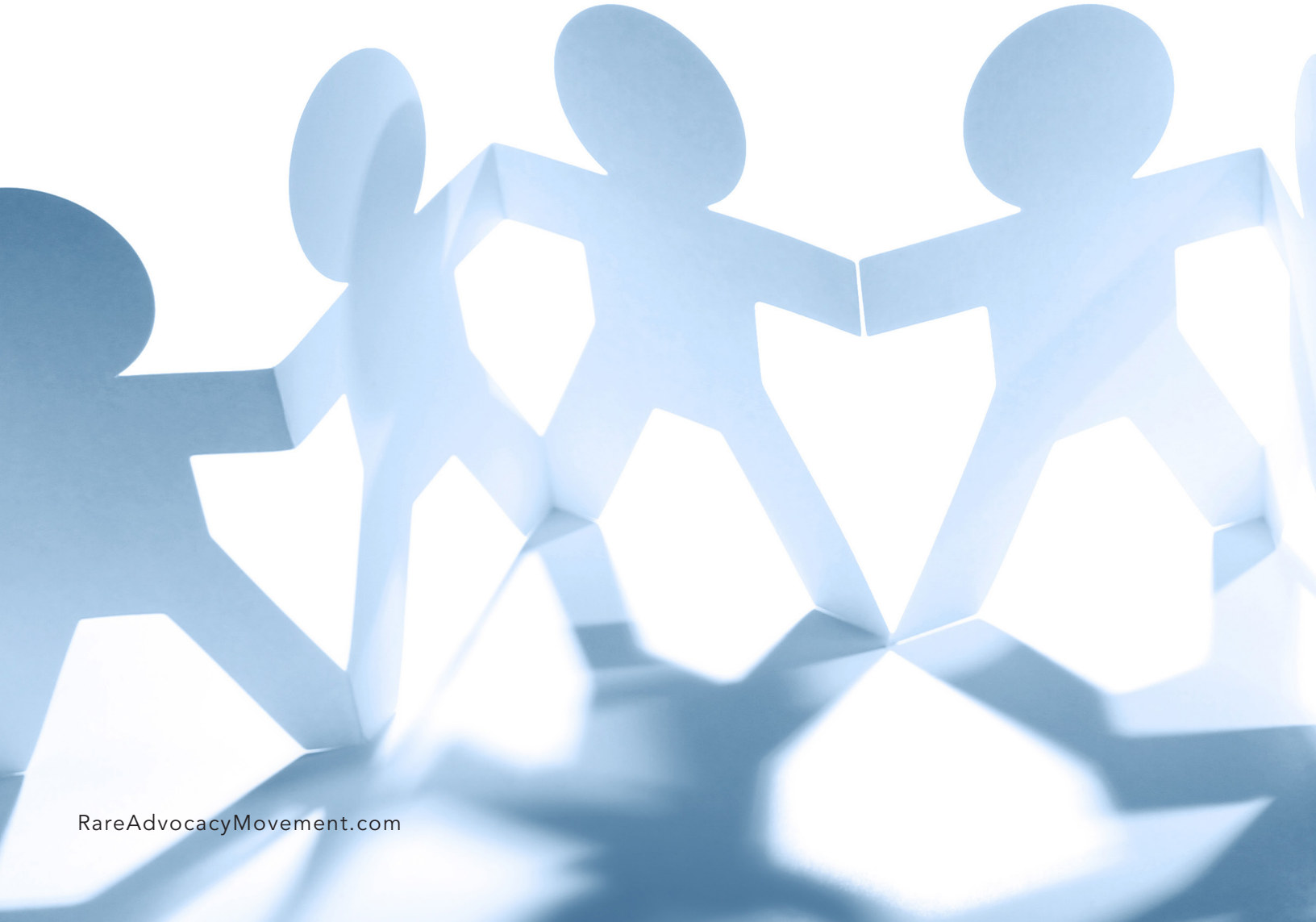
PRIMARY OBJECTIVE

To provide insight on the many burdens patients, caregivers, and families must manage when living with a rare diagnosis.



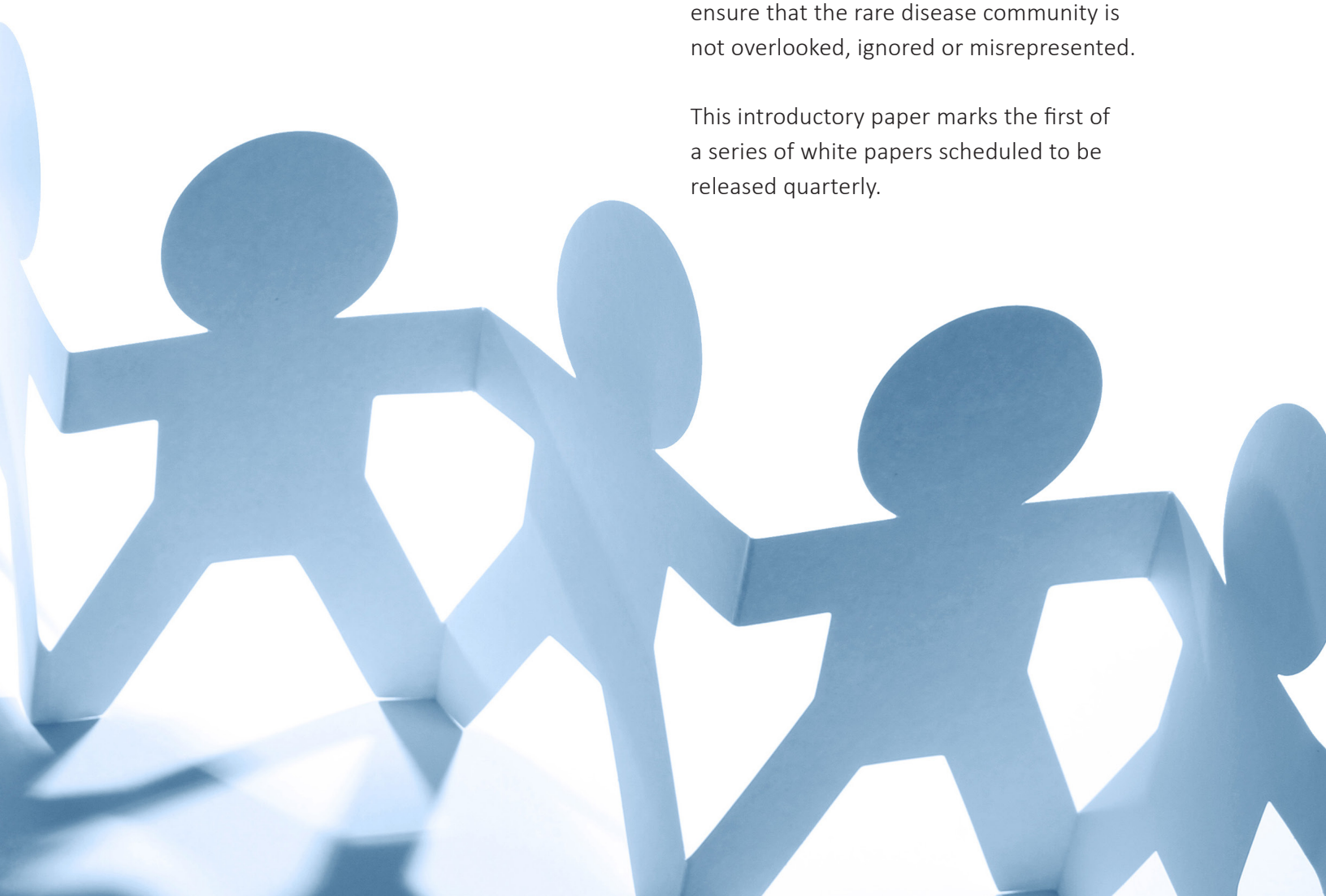
THE RARE DISEASE LANDSCAPE IS COMPRISED OF A NETWORK OF ELEVEN INEVITABLY CONNECTED STAKEHOLDERS.

1. The Patient Community
2. The Care Partner Community (Parents & Non-Parents)
3. Patient Advocacy Organizations
4. Pharmaceutical/Biotech Companies
5. Insurance Providers
6. Researchers/Scientists
7. Academia
8. Healthcare Providers
9. Service Providers (i.e. research organizations, specialty pharmacies, etc.)
10. Regulatory Agencies
11. Independent Consultants

A CENTER OF INSIGHT (COI) FOR STAKEHOLDERS

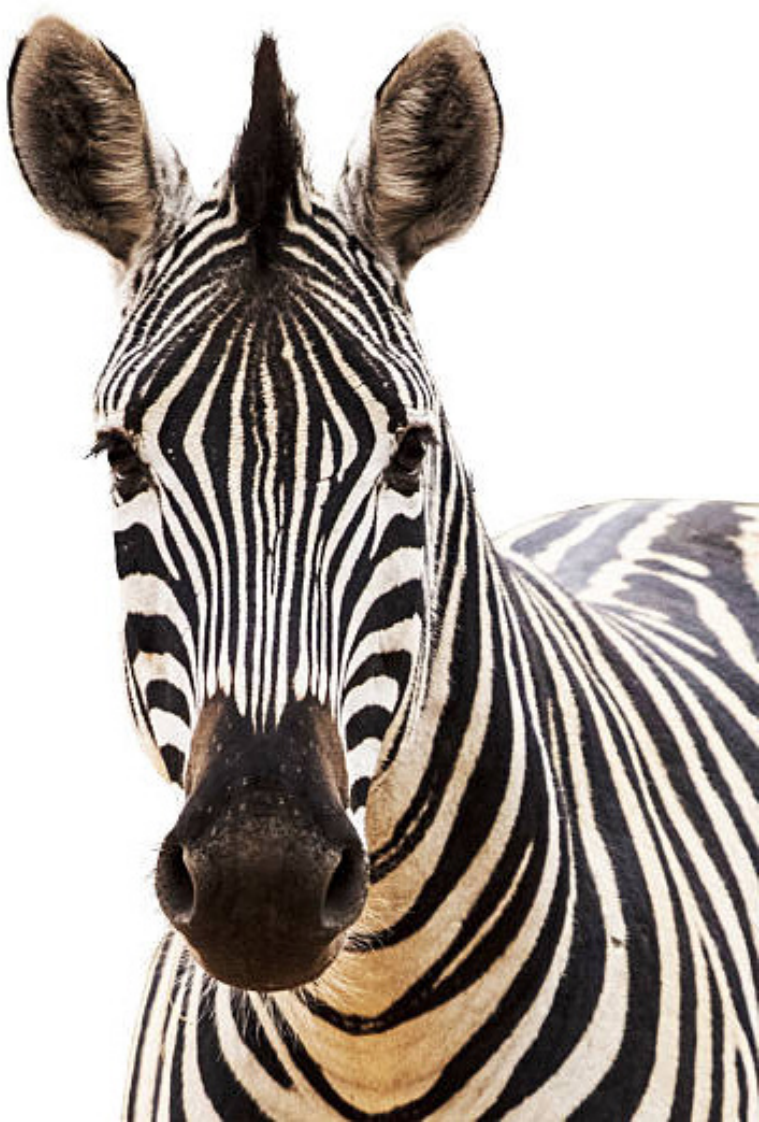
The **Rare Advocacy Movement (RAM)** is an interactive network of morally vetted patient advocacy leaders focused on documenting the complex structure and unique dynamics of the rare disease patient advocacy landscape. RAM's objective is to amplify the real-world voice of the rare disease community in a morally conscious manner, keeping the best interests of the patients and members of their support teams at the forefront of all initiatives. RAM functions on the importance of integrity within the patient advocacy community and aims to support transparency, clarify misunderstandings and ensure that the rare disease community is not overlooked, ignored or misrepresented.

This introductory paper marks the first of a series of white papers scheduled to be released quarterly.



THE PATIENT ADVOCACY PHENOMENON

The physical, emotional, social and financial impact of a rare disease on individuals and families has motivated several advocacy leaders to join forces to form organizations in an attempt to have a positive impact on the understanding of the disease, as well as offer supportive assistance to others affected by the condition. Throughout the healthcare industry, rare disease stakeholders are continuing the mission to enhance collaboration with each other while advancing innovation and patient care. At the very center of this phenomenon is patient advocacy, a role which has become increasingly vital to the success of several healthcare stakeholders. As an influential force revolutionizing care and support for patients and their support systems, patient advocacy is fundamental to embracing patient-focused healthcare. It is becoming essential for stakeholders to align with trusted advocacy leaders in order to effectively navigate the multifaceted rare disease advocacy landscape.



MOTIVATIONS BEHIND EDUCATING THE BROADER ECOSYSTEM REGARDING EFFORTS TO MAINTAIN AND IMPROVE QUALITY OF LIFE

The landscape of drug development has changed in recent years and the value of meaningful patient-focused solutions has increased. Stakeholders must adopt patient-valued strategies across the product life cycle, identify areas for cultural and organizational change, and determine their role in adding value to the patient beyond traditional measures.

In order to enhance the patient experience, stakeholders must understand how patients navigate the rare disease experience holistically. It is critical to embrace an approach of understanding the roadblocks and hurdles faced by patients and their families, backed by the financial and socio-economic barriers that they are forced to endure. Unless stakeholder organizations place themselves in the shoes of the patients, "patient-centricity" will continue to remain a vague altruistic concept the industry strives towards rather than a reality to embrace. Developing a patient-focused strategy requires an in depth understanding of the many burdens patients, their care partners, and families must manage when living with a rare condition, beyond traditional therapeutic interventions.

Different diseases, disease communities, phases of disease progression, and stages of life warrant distinct approaches to patient engagement and integration of patient input. The role of the care partner and family members is extremely instrumental in managing the unpredictable daily challenges levied by rare disease. The concerns and stress factors experienced by supportive individuals who are involved in the patients' daily routines should also be factored into our understanding of unmet needs beyond therapeutic products.

When engaging with patients, it is important to understand that one size does not fit all. One cannot only ask a single patient about their disease-specific experience and expect to gain an understanding of the broader perspective of an entire community given the many variables.

When designing strategies to gain a deeper understanding of the overall disease-specific experience, patient advocacy leaders are often great starting points.

KEY OPINION LEADERS IN PATIENT ADVOCACY WITH VARYING PERSPECTIVES PROVIDE VALUABLE INSIGHTS

RACHELLE DIXON

Rachelle Dixon advocates for Hereditary Sensory Autonomic Neuropathy Type 1E (HSAN1E), a genetic adult-onset condition that has affected a total of 12 known loved ones within her family. In addition to being an active rare disease advocacy leader, Mrs. Dixon possesses several unique perspectives, two of which are highlighted in this white paper, that of a sibling caregiver and that of a daughter to an affected mother. Her experiences offer several uncharted insights into the caregiver psyche and social implications of an adult onset rare condition with no treatment option.

NEENA NIZAR

Neena Nizar advocates for Jansen's Metaphyseal Chondrodysplasia, a rare degenerative skeletal disorder. Mrs. Nizar presents insights from the unique perspective of being a rare disease advocacy leader, a patient herself, and a mother of two affected boys. Mrs. Nizar's insights offer a valuable look into the unseen difficulties that come with caring for two children that are progressively deteriorating physically while their cognitive abilities remain unaffected. Mrs. Nizar describes the rare disease experience as being in a constant state of flux whereas the unpredictability of living with and caring for rare disease children leaves a lasting impact on all aspects of her life.

ANDRA STRATTON

Andra Stratton advocates for all forms of Lipodystrophy and has Familial Partial Lipodystrophy herself. Ms. Stratton is not only a community champion for Lipodystrophy but is a trailblazer in advocacy for the rare disease community at large. Her personal patient perspective highlights the daily balancing act that takes place when managing a systemic metabolic condition and the social implications of physically appearing different as a direct result of her rare condition.

TERRI ELLSWORTH

Terri Ellsworth advocates for Duchenne Muscular Dystrophy, a genetic condition that affects her son who was diagnosed at the age of four and is now thriving at 17 years of age. Mrs. Ellsworth's son, represents a small subset of rare disease people who have experienced success after being enrolled into a clinical trial for a drug that has significantly improved his quality of life and ability to function. She speaks to the mother care partner perspective, providing insight into the experience of gaining access to an efficacious therapeutic product on which her son is doing very well in comparison to other Duchenne patients. Regardless of her son's good fortune, however, he still experiences difficult obstacles and challenges that are important to note and understand.

KEVIN ROHRBACH

Kevin Rohrbach is a dual member of the greater rare disease community. Professionally, he has served in various capacities throughout the product life cycle including patient engagement and architecting holistic patient care programs; while, personally he is a care partner to two immediate family members diagnosed with a rare disorder. To support the development of this paper Kevin investigated four unique patient advocacy perspectives within the rare disease community. The goal was to obtain a broader non-disease specific perspective on the implications of living with a rare disease beyond traditional therapeutic interventions.

FINANCIAL IMPLICATIONS

For both individuals and family members, the economic impact of rare conditions may extend to lost productivity, lost wages, and/or the inability to find manageable work with flexible leave, health insurance, and other important benefits.

When discussing the financial implications of a rare diagnosis, many stakeholders focus on lost income and insurance coverage. While coverage is a significant issue as highlighted by Mrs. Nizar, "I spend a lot of time on the phone with insurance companies educating them on the condition and fighting for treatment coverage," the topic of insurance coverage warrants dedicated research to fully understand it's holistic implications.

Mrs. Ellsworth explains, "When enrolling and participating in a trial, it's a major imposition on the family dynamic. My career was altered and income was drastically affected. And my husband lost his business during the first year of the trial. It is a huge sacrifice and there is no way anyone can understand this unless they live it." Loss of income is a major issue faced by most patients as well as their care partners and has a serious socio-economic impact that RAM plans to explore and document in a future publication.

While some rare disease patients have parents or a spouse as a care partner, there are unique situations where patients are forced to fend for themselves. Ms. Stratton had to leave work due to the challenges of staying healthy, while obtaining an accurate diagnosis of Lipodystrophy and going through divorce proceedings, each of which carries its own financial burdens.

> "I had a real career! I got my Masters in Industrial Organizational Psychology. In my 20's I was a professional student, interned and then went into my career. My job required a lot of energy because I had a high level of responsibility at work. Because of my condition, I didn't have enough energy to do what a lot of 20 and 30-year olds were doing and eventually I had to leave." - Andra Stratton

Beyond the challenges of earning a sustainable income to cover basic living expenses there are the continual worriers associated with costs of assistive devices, home alterations, and other items necessary to accommodate declining physical capabilities, which are not always covered by insurance. Mrs. Dixon explains, "Lisa, my sister, started with needing hearing aids. She then progressed to needing to walk with a cane, to a walker, to the wheelchair. We had to also install additional bars in the bathroom for her when she was still mobile, before needing to purchase diapers when she could no longer safely use the bathroom on her own."

DAILY IMPLICATIONS

There is no question that rare conditions often significantly impact an individual's routine. Typically, the daily impact of a rare condition is the main area of exploration by stakeholders involved in the drug development continuum.

When quantifying a patient's Quality of Life (QOL) there are two standards of comparison that the patient community organically references: one being others of the same age with the same diagnosis, and the second being other healthy individuals within the same age group. According to Mrs. Ellsworth, "compared to most of the population for Duchenne there is so much my son can do for his age. But compared to a typical 17-year-old, there is so much he cannot do."

Standards of care and best practices are ambiguous, if they even exist, given the nature of rare diseases. Ms. Stratton explains her experience of adjusting to her symptoms organically, "the more I ate the sicker I got, so I adjusted my diet before even receiving my diagnosis." She must follow a low-fat diet, and manage triglycerides and carbohydrate intake. "There isn't one diet that works for everyone and even a diet that may work one week, may not work the next week," according to Ms. Stratton.

The implications of travel can have an extended impact on a patient's ability to function after the conclusion of the trip.

> "Traveling is always a challenge, especially when you are dependent on accessible vehicles and pathways that often time aren't available or don't exist."
> - Neena Nizar

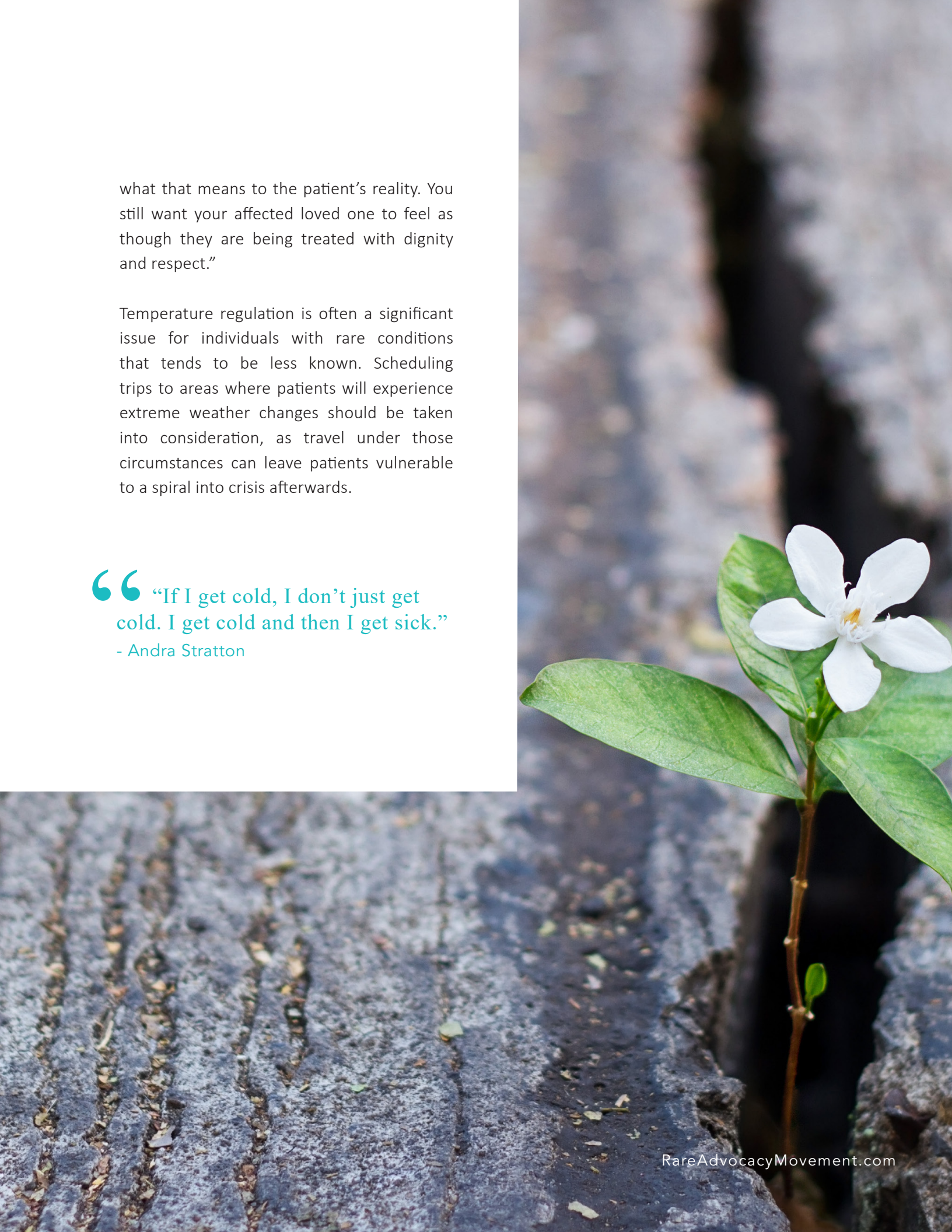
There is a lot of preparation that is often required to travel long distances, whether it's to a clinical appointment or to an advocacy event. Patients and/or their care partners must choose if it is worth up-rooting themselves from their daily routine in order to expend the mental and physical energy necessary to make travel possible. Ms. Stratton notes, "when you travel you don't have control of your own food. Before I travel I have to go out of my way to put my body in its most ideal state in order to compensate for the stresses travel places on it, in addition to bringing extra medications to counter my body's reactions to those stresses of travel." Successful trips include those that factor in appropriate resting points and breaks in the day for patients and their care partners.

Traveling is sometimes a sensitive topic because it may require a patient to accept that their condition has progressed to points where new limitations are placing them at risk for further injury. Mrs. Dixon understands this dynamic very well, "Patients can be ambitious and do not want to always accept their limitations. Caregivers see the need when it presents and have the task of convincing the patient of the need knowing

what that means to the patient's reality. You still want your affected loved one to feel as though they are being treated with dignity and respect."

Temperature regulation is often a significant issue for individuals with rare conditions that tends to be less known. Scheduling trips to areas where patients will experience extreme weather changes should be taken into consideration, as travel under those circumstances can leave patients vulnerable to a spiral into crisis afterwards.

> "If I get cold, I don't just get cold. I get cold and then I get sick."
> - Andra Stratton



FAMILY DYNAMIC AND TRANSITIONS

Approximately 50% of the people affected by rare diseases are children.[7] The other 50% of people affected by rare conditions are, naturally, adults. While some of those individuals have been impacted by an adult-onset condition, others transitioned as an individual living with a rare condition from childhood into adulthood. The transition from child to teen to adult years with a rare disease has not yet been deeply explored in the rare disease community to date. The Rare Advocacy Movement plans to explore these insights deeper for a later publication.

A key family dynamic revealed in discussions with each contributor of this paper highlights the routine sacrifices that are continuously made in order to accommodate limitations inherent within a rare disease household. Such limitations can place traumatic emotional strain on the immediate family members involved in daily household activities, support and interactions.

An important general consensus amongst many rare disease advocacy leaders is that families do not have feelings. Individuals do. Each family member has their unique, individual experience which has an important impact on how they cope and manage the daily stresses of the rare disease experience. Another aspect regarding managing life impacted by a rare condition is it is time-consuming. A compilation taken from each contributor's insights of additional tasks typically added to the care partner(s) overall daily tasks may include but are not limited to:

- Lengthy calls with insurance companies
- Scheduling clinical appointments
- Filling medications
- Driving to medical consultations and appointments
- Installing devices to assist with disease progression
- Managing changes in diet recommended for condition
- Coordinating other family member's schedules around the care for a rare disease patient.
- Adjusting the family's overall food consumption to accommodate patient's special dietary needs
- Trouble-shooting assistive device malfunctions and coordinating the occasional repair and replacement of such devices.

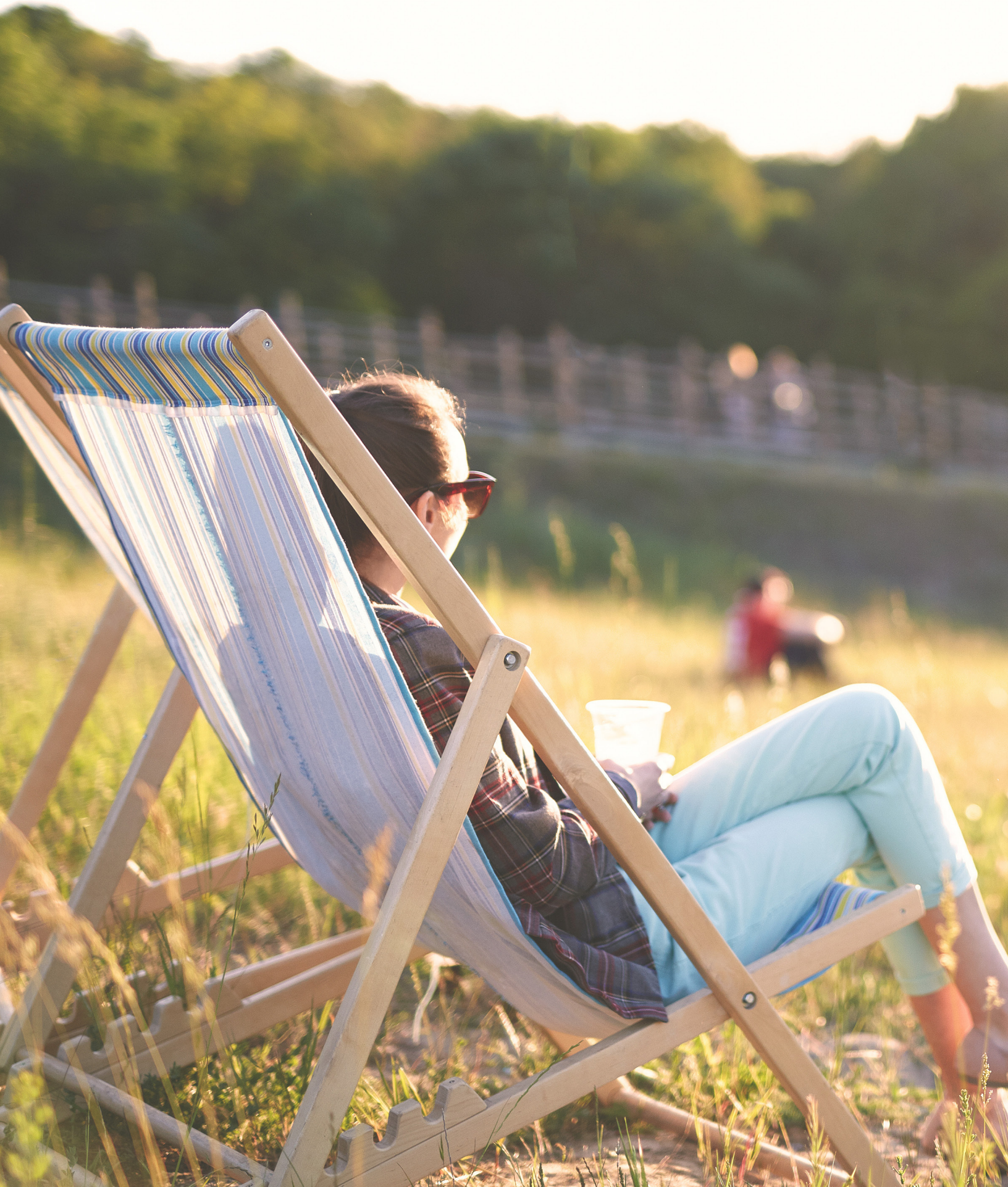
> “This is not your typical lifestyle. Rare disease life takes a huge toll on the overall family dynamic…loss of career, stress. I want people to understand that.”
> - Terri Ellsworth

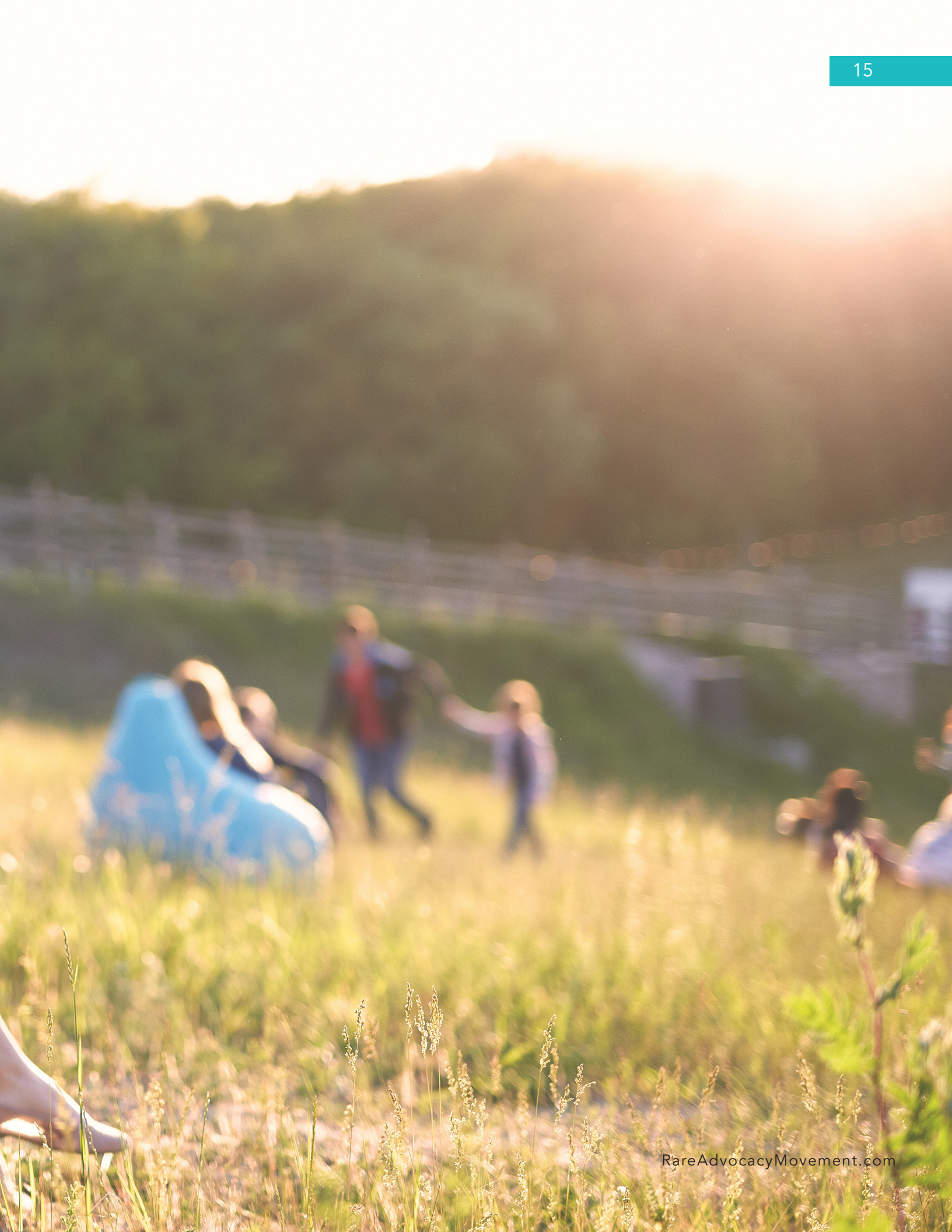
Rare diseases take their toll on all involved. from a mother being pulled away from typical parental duties for a healthy child to a father no longer being able to attend his daughter’s school activities because of his condition. Healthy children being raised in a household that is responsible for the care of a rare disease individual are impacted in ways that tend to go unnoticed due to the tasks that take priority in caring for a loved one. Mrs. Dixon, points to feelings of “survivor’s guilt” after learning that she didn’t inherit the gene responsible for HSAN1E, while two of her siblings did. Siblings aren’t the only ones who at times feel neglected, as Mrs. Nizar notes, “the stress cracks into the marriage. When my husband says I don’t have time for him. It’s the truth! I don’t have time for him. I can see why people get divorced. The glue that binds us together is our mutual love for the kids.”

> “Since the boys have been born, we haven’t taken a vacation or even gone on one date simply because there isn’t enough time in the day outside of care giving.”
> - Neena Nizar

The dynamics of a marriage, when taxed by a rare condition, tend to suffer dramatically increasing the potential for separation. Ms. Stratton, who is divorced, explains that “divorce is often an outcome when you have a rare condition.” Given the common phenomenon of the laborious diagnostic journey, often the symptoms presented by a condition contribute to the degradation of the relationship without either party even realizing the underlying cause. In Ms. Stratton’s case, the relationship had deteriorated before she was accurately diagnosed. She received a correct diagnosis of Familial Partial Lipodystrophy once the divorce proceedings were initiated, at which time the marriage had degraded past the point of return.

> “My disease affected my energy level and my metabolics. It was more of a mental battle. I felt that people around me thought that I had a weak constitution that I was a bit of a hypochondriac, which became an issue in my marriage because my activity level was not as high as my spouse’s.” - Andra Stratton





SOCIAL AND PSYCHOLOGICAL IMPLICATIONS

The social and emotional toll of a rare diagnosis has lasting implications for all individuals involved. The debilitating unpredictability of living with or caring for a loved one with a rare condition, exposes a degree of vulnerability only understood if experienced. Depression can easily develop a stronghold upon those affected as a result of many losses such as:

- loss of income
- loss of independence
- loss of friendships
- loss of a marriage
- loss of physical functions
- loss of biological controls
- loss of the person you once were
- loss of a life you once knew
- loss of the affected loved one

Humans are highly social beings. We begin socializing at very young ages and enjoy the company of loved ones and sharing our personal experiences with each other. The development of friendships and the basic understanding of our social surroundings begins during childhood.[8] Ms. Stratton, while accurately diagnosed at the age of 37, was born with Familial Partial Lipodystrophy. The symptoms she experienced as a child shaped a self-impression of weakness. Like most children with invisible conditions, her initial impression was that other children her age were simply better at managing the same biological experiences. “This disease completely stole my childhood. I thought everyone was managing similar issues and that I was just a wimp.” Ms. Stratton would later learn that her body was unique in that she was unable to appropriately process and store lipids and lacked the protein leptin which contributed to the constant sensation of hunger and mood swings.

The childhood experience of a person born with a rare condition that is visually telling often presents unique social consequences as compared to those that may be living with an “invisible” condition. Mrs. Nizar’s childhood was significantly impacted by Jansen’s Metaphyseal Chondrodysplasia (JMC). Mrs. Nizar reflects, “I was a sick baby. I had over 20 surgeries as a child. My parents didn’t know what to do with me.” Mrs. Nizar’s two children are now living a similar childhood to her own. Mrs. Ellsworth’s son, was born with Duchenne Muscular Dystrophy (DMD); and while he is

one of the lucky few to have been enrolled in a clinical trial, ultimately experiencing a significant decline in the progression of the disease, he is not your average looking 17-year-old. Mrs. Ellsworth shares, "the emotional side of Duchenne can be as much of an issue as the physical challenges. Since first grade, he has seen an emotional support counselor. Most Duchenne patients are on antidepressants and anxiety medications." Literature suggests 1/3 of DMD patients experience self-depreciation, sense of insecurity, marginalization and isolation, depression, and marked states of anxiety.[9] However, according to Mrs. Ellsworth, a few clinicians believe this number could be as high as 40-50% among similar patients.

Mrs. Ellsworth can count on one hand the number of birthday parties her son has been invited to during his school age years. This seems to have a greater impact on Mrs. Ellsworth as a mother than it does her son, as she explains, "this is the only life he knows. He knows no other way."

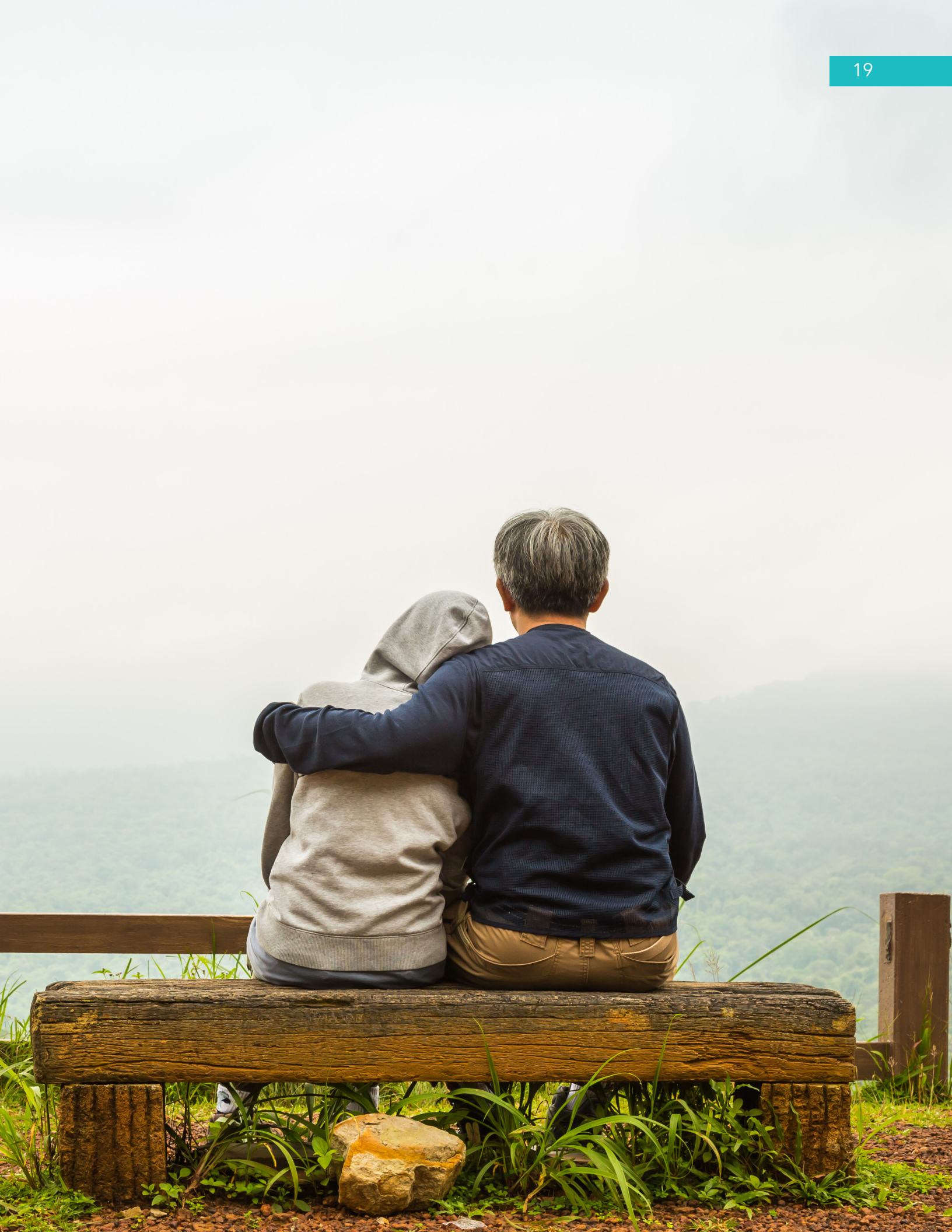
As rare disease children age into young adults, the limited social interactions can take a significant toll both psychologically and/or emotionally, especially when the condition results in noticeable disabilities. In Mrs. Nizar experience, "people tend to rush to judgment as to what your cognitive capabilities are when you have a disability," and sometimes people's judgmental reactions and comments can leave the affected individual feeling less human. This social disconnection often expressed by various members of the rare disease community spills into the already difficult task of identifying romantic partnerships. Mrs. Ellsworth recalls her son's exact words, "I'll probably never have a girlfriend. I'll probably never get married." According to Mrs. Ellsworth, the reality of potentially never having a girlfriend or getting married due to his condition, bothers him more than his physical appearance. For those individuals with rare conditions that are less obvious, the act of obtaining a date or a life partner may not be where the difficulty lies. Ms. Stratton notes the difficulty lies in seeking a potential long-term partner willing to accept the individual and implications that may come with having a rare condition. At times, it can be vulnerable for the individual with a rare condition to open up about the realities of their condition. The dating experience can often leave rare disease patients with feelings of shame and not being worthy of human connection.

Not all rare disease patients share the experience of having difficulty finding a long-term partner. Those who have partners, whether before or after a diagnosis may experience difficulty staying in the relationship as a direct result of the added stresses of the rare disease experience. For most rare disease patients, the isolation, the uncertainty about the course of the disease, and the frequent lack of effective treatments can have a significant impact on the patient's overall psychological and emotional health.

Some rare conditions result in premature

death of infants and young children while others are progressively debilitating and ultimately fatal in adulthood. Such premature deaths after caregiving can have lifelong effects on parents, siblings, grandparents, and others close to the family.[10] After Mrs. Dixon's sister passed away from HSAN1E, she immediately was thrown into caregiving for her brother who was also diagnosed with the same condition. After the death of her brother, Mrs. Dixon sought out a counselor, "after my brother passed away, I had some difficulty functioning and I ended up going to a counselor and they diagnosed me with PTSD. I still actively try to manage it." As a way of coping with her devastation, she founded the HSAN1E Society with her surviving sister. In the absence of support groups or community leaders offering support and guidance relative to a particular condition, rare advocacy leaders are often born.

> "When you get diagnosed with a rare disease, you are told good luck to you. I didn't want another family to go through what my family and I went through alone anymore."
> - Rachelle Dixon



THE ROLE STAKEHOLDERS CAN PLAY IN ASSISTING PATIENTS OVERCOME THE HOLISTIC TOLL LEVIED BY RARE CONDITIONS

ALIGNING WITH THE ADVOCACY COMMUNITY

When working with the rare disease community, one of the biggest mistakes an organization can make is assuming they have a complete understanding of what the patient experience entails and the unmet needs that exist in the community. Referencing a generalized rare disease experience, and not making the effort to foster genuine relationships with the specific community will likely result in misconceptions and faulty understandings. Rare disease communities and/or leaders are often willing and able to partner in a manner that promotes results that benefit all stakeholders. It's important to demonstrate a willingness to invest in a respectable, ethical and transparent collaborative relationship. In order to ultimately support patients and caregivers, as well as create awareness for treatments, organizations must thoughtfully align advocacy priorities with internal strategies, establish bridges across functions, and achieve an overall cultural shift. By aligning advocacy with organizational priorities, teams can strengthen relationships across the rare disease landscape, achieve objectives and ultimately support patients in the most effective means possible.

TIME IS EVERYTHING TO PATIENT ADVOCATES AND EFFICIENCY IS KEY TO SUCCESS

Most patient advocates function on the premise that tomorrow is not promised today, making them productive and efficient partners. The time patient advocates spend explaining and reliving personal experiences to advance patient-focused strategy development and research and development (R&D) efforts is extremely valuable. When afforded respect and treated with integrity, patient advocates can become loyal constituents and professional allies for stakeholders who genuinely strive to establish a patient-focused culture. Trusted leaders are sources of valuable insights and can assist in defining efficient and effective ways to expand beyond static disease information. They can also serve as tremendous resources when, adapting and validating the patient-centeredness of Patient Reported Outcome Measures, or developing cases for existing and future endpoint measures.

As a collaborative network of rare disease focused advocacy leaders, RAM has identified three immediate call to actions to advance patient-focused decision-making across R&D and care delivery. These efforts both build on ongoing activities and initiatives and require new collaborations. RAM is ready to work across stakeholder groups to move these efforts forward.

1. Explore and publish findings on topics of interest established by a consensus of trusted rare disease advocacy leaders

2. Define the Return on Investment (ROI) on truly patient centric advocacy initiatives and programs

3. Develop and publish blueprints of successful collaborative efforts utilizing real world evidence (RWE)

In sum, rare diseases have a profound impact on patients and families. Patient advocacy leaders, can band together to influence the world around them in an organized effort to inform and benefit their communities, influence public policy, stimulate research, and guide patient-centric efforts. As this white paper illustrates, collaborative partnerships with focused and trusted patient advocacy leaders provides for new opportunities to accelerate progress.

RAM

RARE ADVOCACY MOVEMENT

RAM is a charitable network of morally vetted rare disease patient advocacy leaders working together to strengthen the patient advocacy voice through meaningful stakeholder collaborations. 2018 officially launches the Age of the Empowered Patient Advocate.

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Graphic Design by JasleniDesigns.com