

## Maximizing Our Potential:

### Exploring the Ecosystem of Peer Support Services to Better Meet the Needs of Families Living with Pediatric Neurologic Conditions

One in six children is living with a neurologic condition. In 2017, the Child Neurology Foundation (CNF) established the Family Support and Empowerment Program (FSEP), a peer support program for families affected by neurologic conditions. FSEP provides free, direct connections to trained Peer Support Specialists, who connect with families 1-on-1 via email, or other technology (e.g., telephone, social media messaging, video conference). FSEP was founded in the recognition that comprehensive, compassionate support for families facing rare and challenging diagnoses extends beyond traditional health care services.

Families seek and need the company of others who have made similar journeys with their children, to address the isolation many feel and to offer the wisdom of experience and hindsight. Families also benefit from guidance in identifying credible medical information online and navigating the various patient advocacy organizations. CNF's FSEP Peer Support Specialists are parents themselves but are not medical professionals nor do they offer medical advice. In addition to emotional support, Peer Support Specialists offer curated resources and linkages to additional advocacy organizations.

FSEP is intended to serve as a complement to health care services, and Peer Support Specialists seek to partner with health care providers, supporting caregivers as they learn about the disease state, work with health care providers to ensure the best available treatment for their child, advocate for their child in education and social service settings, and help to advance the understanding in treatment.

Since its inception in 2017, FSEP has received over 360 inquiries, from 45 states and 47 countries around the globe. Child neurology practices and other patient advocacy organizations have referred families to FSEP; families have also identified CNF and FSEP through their own Internet research. Through FSEP, caregivers connect to a trained Peer Support Specialist, who shares his/her personal experience as a parent of a child with a neurological condition, and who has received training in appropriate models of peer support and common aspects of neurologic disease. CNF is building a curated resource library of materials addressing specific conditions and concerns.

In 2018, CNF was awarded a Patient-Centered Outcomes Research Institute (PCORI) Tier A Engagement Award to conduct a national needs assessment of peer support services in the child neurology community. Comprised of a literature review and semi-structured interviews with 11 patient advocacy organizations in the child neurology space, this needs assessment provides a description of the current peer support services offered by other organizations in the child neurology community. The needs assessment includes a consideration of the challenges faced by the organizations providing or seeking to provide peer support services, and a discussion of what is needed to strengthen, build, and better embed peer support services in the lives and care of patients and families living with pediatric neurologic diagnoses.

In addition to describing the landscape beyond FSEP, CNF seeks to employ the insights of others in the child neurology community to assess and test FSEP's provision of peer support services. While FSEP's services are clearly valued by the families that utilize them, CNF seeks to better understand whether and how these services address the unmet needs perceived by others in the community, to better target those services, and better partner with colleagues.

## **The Interviews**

Sixteen representatives of 11 patient advocacy organizations that address pediatric neurological conditions participated in semi-structured interviews, conducted in March and April 2018. (Participating organizations and the interview instrument are available in the appendix.) Interviews were divided into two parts: for the first part of the survey, organizations that provide peer support services were asked to describe those services, while organizations that do not offer peer support services were asked about their interest in doing so, and about the unmet community needs that might be addressed through peer support services. All the organizations were asked to respond to the second portion of the survey, to share their perception of the status of peer support services in the child neurology community.

### Interview Organizations and Respondents

The organizations interviewed differed in size, scope, mission, and history. Two of the organizations— the Tuberous Sclerosis (TS) Alliance and the Batten Disease Support and Research Association (BDSRA)—were founded more than 30 years ago, in 1974 and 1987, respectively; most were founded in the 21<sup>st</sup> century, after the rise of social media: technology that enables some of the most common peer support modalities. Some organizations define their audience within a specific disease or treatment community: the Dup15q Alliance requires confirmation of this diagnosis before engagement in their peer community; the Brain Recovery Project Childhood Epilepsy Surgery Foundation (BRP) focuses on families and patients facing or recovering from various epilepsy surgeries, such as hemispherectomy. Other organizations, such as Global Genes and BDSRA, seek to serve broader communities, and define their services to include linking families and patients to other organizations with in the “ecosystem” of child neurology.

While all the organizations interviewed for this needs assessment were founded by families affected by neurologic conditions and most provide direct service and support to families, some have mission statements focused on support of research toward a cure or treatment. These include the Hereditary Neuropathy Foundation (HNF), BRP, the International Alliance for Pediatric Stroke (IAPS), and the Children’s Tumor Foundation (CTF). Other organizations place services for families and patients foremost in their mission.

All respondent organizations utilized volunteers in some capacity; eight of 11 engaged researchers and/or physicians and/or industry representatives to serve on Scientific, Medical, and/or Corporate/Industry Advisory Boards. Most employed paid staff; the Association for Creatine Deficiencies (ACD) and IAPS operates through an all-volunteer board structure. Interview respondents included organizational staff leadership: Executive Directors/CEOs (6), founders (4), current and former Board members (5), and staff leaders for peer-focused services (9); in 6 cases, respondents served in multiple roles.

## **Interview Findings**

### **Individual Organizational-focused Questions**

Three of the 11 interviewed organizations—Global Genes, HNF, IAPS—reported that they do not offer peer support services. One of these three, Global Genes, noted that opportunities for peer support are provided at organizational gatherings. Global Genes and HNF both expressed interest in developing peer support services; IAPS refers families to other organizations for peer support, and does not intend to provide these services directly. All three organizations that state they do not offer peer support services nevertheless host social media communities through which families affected by neurologic conditions can meet and communicate with one another.

## Defining Peer Support Services

The first interview question was intended to objectively distinguish organizations that provide peer support services from those that do not; in the absence of a clear, shared definition of peer support services, that objective division was not achieved. Organizations were divided based upon respondents' initial answer to the question, "Does your organization provide peer support services." Only those eight organizations answering in the affirmative were asked to offer a definition of such services.

Four organizations offered objective definitions of peer support; three of these definitions included reference to assistance offered or received by a single individual (emphasis added).

"A caregiver looking for another caregiver I can lean to for support."

"Support provided 1-on-1 by one individual to another."

Meeting the desire "to connect with someone that understands what they are going through"

Support given by those "who get it," who "understand my child"

The remaining four organizations offering peer support provided implicit definitions through the services they described. Here, too, the idea of an individual providing support to a patient, parent, or family predominated: the LGS Foundation (LGSF) provides an Ambassador Program, staffed by parents who contact families within their designated region of service. BRP's Special Education Advocates accompany parents to school meetings where Individual Education Plans are developed. ACD Board members serve as mentors to families who call or contact the organization through its website. BDSRA likewise offers mentors for families who request individual support.

Some organizations appeared to include a programmatic aspect to their definition of peer support. HNF, for example, noted the challenge of screening individuals who would provide peer support as among the reasons HNF does not currently offer these services. LGSF noted the challenge of

measuring program outcomes. BRP describes its Special Education Advocacy Program as the “official” peer support program, noting that Parent Connect, through which families are introduced to others in similar circumstances is “not part of formal program planning.” Each of these statements conveys expectations of how a program is established, executed, and assessed.

The titles assigned to persons providing peer support may imply the expectation of expertise, or of a clear scope of responsibility for those providing peer support services. In addition to the titles noted above, the Dup15q Alliance uses “Regional Representatives” to engage families; BDSRA identifies “Buddy Families” to meet and orient families attending their Annual Meeting for the first time. Using such language may serve to differentiate peer support from friendship, and may communicate expectations to families receiving peer support.

#### Peer Support Services Provided

All the organizations that provide peer support services, as well as the three organization that claim not to provide peer support services, offer families social media communities. All the organizations that provide peer support services, and Global Genes, organize opportunities for families to gather at large organizational meetings. Seven of these central gatherings are held at least annually; BRP currently hosts a gathering every other year. In many cases, these annual/biennial meetings are hosted in different cities each time, to facilitate access for families in different regions of the country. Many organizations provide stipends to assist families in meeting the cost of attending a central meeting; four of the eight organizations that offer peer support services host regional or local gatherings as a means of helping affected families connect with one another.

Table 1  
Types of Peer Support Services Offered

Peer Support Service/Opportunity	Number of Organizations
Social Media Community (e.g., Facebook)	11*
National/International meetings (all held in U.S.)	9*
Targeted introductions	6
Titles/Roles for peer support providers	4
Local/Regional meetings	4
Targeted services/populations	4

\* includes organizations that state they do NOT offer peer support services

Targeted introductions are a strategy employed by 75 percent of the organizations to provide families a specific contact in the disease community; ALD Connect and TS Alliance organize opportunities (social media communities, gatherings) at which families might introduce themselves to one another. In many cases where targeted introductions are provided, families are linked to other families in their geographic area, or to families facing similar issues. Four of the organizations that provide peer support services connect families to individuals identified to play a mentorship role; these mentors may have special training, in special education advocacy, for example, or may play leadership roles in the organization. Where introductions are not intended to initiate mentorship relationships, they may nevertheless provide opportunities for peer support, when and if families “click.”

Services targeted to specific population within the disease community also serve to “localize” peer support. The CTF, for example, hosts a camp for pediatric patients; BDSRA provides programming for siblings and grandparents of patients and for bereaved families. The TS Alliance offers peer support

specific to dependent adults and newly diagnosed families; ACD hosts separate Facebook communities for each of three disease groups. The other organizations providing peer support services also acknowledged the value of connecting families at similar stages of their disease journey, and providing particular expertise to address common challenges, such as entering school or negotiating IEPs.

### Accessing peer support services

Families generally access peer support services through an email or telephone contact with the organization. Five organizations described these contacts as primarily emerging from research families conduct on the Internet, which leads them to the organization's website or Facebook page. The TS Alliance and CTF both place representatives at clinics, where they meet families and provide information on the organization, including the availability of peer support service. LGSF noted that social workers and other parents often refer families to its services, including peer support.

Five organizations reported that physicians refer families to their organizations, and sometimes to peer support services. The Dup15q Alliance remarked that physicians often provide families with information printed from the Dup15q Alliance website, although specific referrals to the organization are more likely to come from genetic counselors. Three organizations reported that physicians rarely refer patients; one respondent reported being "shocked at how little it's done;" another respondent noted the need to remind the physicians who serve on their own Advisory Board to refer families to the organization. Two organizations employ social media advertising to connect to families.

Three organizations described specific protocols or individuals—staff or Board—through which families are linked to peer support services. The Dup15q Alliance, for example, requires verification of a patient's diagnosis before families are introduced to Regional Representatives and the social media community.

## Training and Infrastructure

All eight organizations which provide peer support services described some form of training, education, or guidance that is provided to at least some of those who provide peer support. In many cases, the goal of the training appears to be providing information to peer support providers to pass on to families. Where training content was described, it tended to focus on the content of peer support conversations: “the organization as a whole” (ACD), “advances in research and medical care” (Dup15q Alliance), “being an adult with TSC” (TS Alliance).

Information about the organization was often described as being offered only once, in an introductory capacity. Information on disease states, as well as scientific or medical materials, tends to be offered at all relevant gatherings, whether virtual or in-person. Some organizations host regularly scheduled topical trainings or updates: BRP, for example, conducts biweekly training for its Special Education Advocates; TS Alliance holds monthly conference calls which include a question and answer time for volunteers. Several organizations noted that staff are “available,” should volunteers seek guidance. TS Alliance reported providing referrals to further training, from state ARC programs and state Peer Training and Information Centers.

Four of the organizations interviewed spoke specifically of training people in methods of providing peer support: three provide outlines or guidelines describing the expectations of peer support providers. One consistently reinforces the need for “radical acceptance” in presentations to staff and volunteer peer support providers; another provides volunteers a handbook that addresses “how to talk about” the organization, the condition, and available resources.

Each of the organizations interviewed was founded in a peer support context—by families who came together to address needs they identified in their disease community. Three of the organizations

providing peer support services identified their founding as the impetus for doing so; five implied some level of needs assessment informed their continued provision of peer support, or the development of formal peer support structures. Costs for peer support services were incorporated in the general operating funds of the organizations; peer support services were variously provided under the umbrella of patient or family education, patient engagement, patient advocacy, or outreach programs and services.

Learning, Challenges, Strengths

The organizations providing peer support services were asked to comment on what they had learned from this work, the challenges they encounter in it, and the strengths of their programs. Common themes emerged in the responses to these three questions: the breadth the task, the human aspects of peer support, and the role of information were noted as challenges, points of pride, and aspects of learning by respondent organizations.

Table 2  
Themes of Challenge (C), Strength (S) and Learning (L) in Proving Peer Support

Theme	C	S	L
<b>Breadth of the Task:</b> Providing peer support to families separated by geography, at different ages and stages of the disease, often with a small staff	5	2	3
<b>The Human Aspect:</b> Managing conflicts, choosing good peer support providers, celebrating the “passion” of stakeholders	2	3	5
<b>The Role of Information:</b> Educating families, countering false information, preserving patient expertise and experience, “arming parents with knowledge”	5	2	2

(Organizations provided multiple responses to each question)

**Breadth of the Task:** All the organizations spoke eloquently of the importance of peer support for families facing pediatric neurological diagnoses. One noted that the “main complaint [of families] is not

the symptoms, but that they feel so alone” (ALD Connect). Another stated, “we believe [families] going through this by themselves is the greatest cruelty;” families were described as “broken” by some diagnoses (BDSRA).

Meeting these needs was noted as a challenge for five of the eight organizations providing peer support services. “Not everybody’s peers are around the corner,” one respondent remarked (Dup15q Alliance). Organizations also noted learning or struggling with the understanding that families require different kinds of support when first diagnosed, when caring for small children or adolescents, when embarking on new treatments, when entering school. Different generations are comfortable (or uncomfortable) with different styles and platforms of support. Several organizations reported straining their staff to meet these variety of needs; one identified funding as a challenge—which may be another perspective on staff capacity.

One organization remarked on their strength in managing the myriad these challenges, through clearly defining the organization’s “niche” (CTF). Another identified program growth as a strength.

**The Human Aspect.** Organizations noted the challenge of managing conflict among volunteers and disappointment from patients and families. One organization remarked that “empathy wanes” among families after years of living with a diagnosis; newly diagnosed families can be put off by this attitude, or frightened by the reality of the years ahead (Dup15q Alliance).

Organizations reported learning to lower their own expectations: “some families jive...and some don’t” (Dup15q Alliance). They also reporting improvements in their ability to “make better matches” (BDSRA), and increased sensitivity to the need for “care in choosing” peer support providers (LGSF).

Invited to identify the strength of their peer support services, most organizations spoke of the people involved: families, board members, peer support providers. “They have a heart of gold and want to make a difference,” one organization said of its peer support providers (LGSF). Another noted the widespread “desire” among families, “that someone else not have to experience some of the things you've had to experience” (TS Alliance).

**Information.** Organizations remarked on the challenge of meeting families’ desire for information. ACD reported that it is not uncommon for families to wait “3-6 months” between diagnosis and their first appointment with a specialist. During this time, families often actively seek information on the Internet; rooting out false information and “unhelpful conjecture” was identified as a challenge faced by Dup15q Alliance and other patient advocacy organizations.

Organizations reported learning more about the need to “arm parents with knowledge” (BRP), and to preserve “patient expertise and experience” (ALD Connect). Convincing physicians to attend to that expertise, or to accept information provided from the organization through parents, was noted as a challenge to patient support. As noted above, LGSF spoke of the challenge of measuring outcomes for peer support services; such measures might increase the credibility of these services and the perspectives of those who provide them.

BRP noted the “extreme reliab[ility]” of the information it provides as a strength of its program. CTF noted that it identifies centers of excellence, thus assuring high quality education and treatment for families. Dup15q Alliance noted the value of social media as a means of rapid dissemination of information to families.

## Community-focused Questions

All eleven patient advocacy organizations were asked questions regarding peer support services in the child neurology community. Two questions addressed perceptions of peer support services: how well-known they are in the child neurology community, and whether they are perceived to be credible, evidence-based interventions. Several questions explored how peer support services might be strengthened, advanced, and supported within the child neurology community. Two questions asked organizations to comment on the relative advantages of face-to-face and virtual peer support.

### Perceptions of Peer Support

Organizations were divided regarding how well-known peer support services are, with five organizations noting some general familiarity with the concept, and four remarking on the community's lack of knowledge. Peer support "hasn't even scratched the surface in becoming a valued resource," reported one. Even those who asserted that peer support services were known allowed room for increased awareness. Another organization described peer support's acceptance as "getting better." A respondent noted that families are aware of and seek out peer support services. Three organizations specifically noted physicians as community members who are unfamiliar with peer support.

Two organizations did not directly address the question asked. One implied a general lack of familiarity with peer support, in asserting that peer support should be a first-line response to diagnosis, recommended by physicians. The other noted that they themselves do not use the term "peer support," preferring to address "patient support" through a variety of services.

The interview question regarding the credibility of peer support services was stated in a manner that appears to have misdirected some respondents. Organizational representatives were asked, "In

your opinion, is peer support perceived as a credible, evidence-based intervention...” Three respondents offered their own opinion of the credibility of peer support, rather than their opinion of the community’s perception of its credibility. Another respondent described peer support services as “critical” and “healthy.” Asked whether this perspective was widely shared in the child neurology community, the respondent said she felt it was.

The nature of evidence and the context of credibility were also raised by respondents as they addressed this survey question. Two organizations noted that the social sciences utilize different evidence than does medicine. Two respondents expressed unease with the notion of scientific validity for peer support. One respondent stated that she hesitated to call peer support “evidence-based, in the true sense of scientific rigor.” Another suggested peer support may be “inherently unscientific.” While four organizations specifically noted that families value peer support, one noted that families can also hold narrow definitions of rigor or evidence: “families find it very valuable, and don’t think through why it is very valuable.... Many people think ‘it’s just hand-holding.’”

Only one organization clearly asserted that peer support is seen to be credible and evidence-based, but three others spoke of this credibility increasing. BRP noted that scientific papers are beginning to address peer support; IAPS spoke of the need for “further” validation—implying the current presence of some validity. ALD Connect tied the increasing credibility of peer support services to the shift toward patient engagement in medicine.

### Advancing Peer Support

Three questions asked respondents to consider how peer support services might be expanded within the child neurology community: how provision of the services might be “furthered,” what “opportunities” exist for peer support services, and what is “lacking” in the child neurology community’s

provision of peer support services. Two central themes emerged from these discussions: technical assistance to increase peer support services, and increasing awareness of peer support services.

**Technical Assistance.** Eight of the eleven organizations suggested that technical assistance in the provision of peer support services would be helpful. Organizations noted a desire for training, templates, and toolkits for launching and managing peer support services. The Child Neurology Foundation was invited to take a central role in these efforts, creating an “ambassador” program or “charters” through which CNF’s technical expertise could be transmitted to local communities or other organizations to advance peer support programs.

Five of the organizations interviewed spoke of the value of collaboration and coordination as a means of advancing peer support services. Opportunities to share learning and reduce duplication of efforts were noted. Providing a “united front” for the rare disease community, and increasing access for families were also mentioned as advantages to working together. Access to peer support services was noted by two organizations as an unmet need in the child neurology community. HNF noted that better coordination of peer support services might increase the likelihood of physician referrals, if, for example, such coordination resulted in a single point of contact, through which families might be routed to the services they need.

One of the interview questions asked specifically whether the child neurology community needed guidance in providing peer support services. Unsurprisingly, given that so many organizations suggested technical assistance, all respondents endorsed the value of more guidance in providing peer support. Five organizations specifically supported the development of a shared definition for peer support.

**Increased awareness of peer support services.** Eight organizations interviewed identified increased awareness and education efforts as strategies for advancing peer support services. Five organizations recommended awareness and education campaigns directed at the community as whole; two noted the need for patient and caregiver education; and four organizations recommended education targeted to physicians. HNF, for example, identified “getting neurologists on board” as a primary strategy to further the provision of peer support services; another respondent spoke of “normalizing” peer support for physicians and families by including it as a part of treatment planning. LGSF and ACD both suggested placing peer support providers in hospitals or clinics, thus incorporating these services in the context of other care and increasing engagement with both health care providers and families. IAPS suggested providing occasional invitations for physicians to observe peer support gatherings, to provide them the opportunity to gain insight into the many challenges their patients and families face.

Organizations were asked to specifically comment on the potential impact of referrals from health care providers to peer support services. Ten of the organizations responded to this question, and all of them stated that such referrals would make a profound and positive difference. Organizations noted that referrals from health care providers would communicate trust in and the credibility of peer support services and patient advocacy organizations; ALD Connect noted that “families are wary of where information comes from,” particularly when that information is found online.

BDSRA remarked that referrals could “shorten the time [families] feel...isolated,” noting that some families spend “years...thinking they are the only ones.” Organizations noted that some families may not be immediately interested in peer support; several suggested that a referral from a health care provider could assist a caregiver in recognizing their need for support, or in recognizing that need more quickly. ACD suggested that families would be more likely to retain information on peer support services, if the information was provided by a physician. In this case, a family that later becomes willing to engage peer support services would have the referral information on hand.

Three organizations—HNF, BDSRA and IAPS—suggested that referrals from health care providers to peer support services might support the work of those providers by lessening the load upon them and providing them a broader, more holistic view of the needs of their patients and families.

### Funding Peer Support Services

Asked to identify potential funding sources for advancing peer support services, organizations suggested **private funding** from individuals and families (5), foundations (2), and memorial funds (1); **corporate funding** from pharmaceutical companies (3), hospital groups (1) and other corporate supporters (1); and **government funding** (5), including from PCORI (3). Global Genes and BRP both noted the effort required to apply for government funding; Global Genes suggested a cost-benefit analysis might be necessary before such an endeavor.

IAPS suggested that local hospitals or advocacy organizations might provide in-kind support, such as meeting space or refreshments for peer support gatherings. ACD suggested that patient advocacy groups might share the results of their funding research, especially when another organization is better suited to a funder's interest or requirements.

### Face-to-Face and Virtual Peer Support

Peer support services in the child neurology community are profoundly shaped and enabled by the technology of the Internet and social media. Even those organizations that do not claim to provide peer support maintain websites through which families learn about the organizations, and host social media communities through which families meet one another and, presumably, provide each other some sorts of support. The development of Internet and social media technology enables the

development of rare disease communities by providing the means through which families separated by vast distance can nonetheless come together. These technologies allow many of the organizations participating in this needs assessment to achieve a global reach.

Organizations were asked whether peer support services are more effective when provided in a face-to-face setting or virtually; they were also asked to comment on circumstances to which one mode or the other might be best suited. Five organizations noted strengths of both methodologies, depending upon circumstance or the individual. One respondent remarked at how social media had transformed the dating world, and asserted that “a real connection” can be made through email or social media.

Eight organizations endorsed the power of face-to-face connections, noting that meeting in person “makes a huge difference for kids and families” (IAPS) or asserting that face-to-face peer support is “hands-down” superior to virtual encounters (TS Alliance). Organizations noted that face-to-face meetings allow non-verbal communications, and are “better for providing emotional support” than meetings mediated by technology (IAPS, BRP, Global Genes). Face-to-face encounters were noted as an impetus for organizations’ central or regional meetings, and were described as “strengthening” relationships initiated online, taking them to “a new level.” Four organizations noted the positive impact of personal presence at hospitals, clinics, and funerals.

Six organizations acknowledged that virtual peer support is more accessible and feasible than face-to-face encounters. Respondents noted distance, the challenge of finding sitters for children, and health concerns, such as compromised immunity, which are mitigated through social media or other virtual connection. Two organizations—BDSRA and HNF—noted that virtual peer support may be preferable for families who feel overwhelmed by their diagnosis. HNF suggested that, for some families, a virtual connection is the first step toward in-person engagement. ALD Connect, which serves a

community that includes adult patients, noted that virtual connections may make it easier for patients to discuss “sensitive issues,” such as urinary or sexual dysfunction.

Organizations also acknowledged that “desperation occurs” at times when face-to-face peer support may be unavailable: “a lot of nights when [my son] would be seizing uncontrollably, I’d be sitting by his bedside...but I’d also be on my laptop, crying out, seeking answers” (LGSF). ALD Connect noted, “you might be sitting bolt upright in bed—the Internet is where you go.” Most organizations interviewed serve a global community; virtual peer support is the only viable strategy for connecting to all the families they serve.

None of the organizations interviewed suggested doing away with virtual connection. While face-to-face peer support was seen to be most effective in reducing family’s feeling of isolation, two organizations noted that virtual connections are convenient and appropriate for sharing resources or information. Most saw the two modalities as “complementary” (CTF). BDSRA offered the analogy of a vaccine, with face-to-face peer support as the “initial shot” and virtual peer support serving as the “booster.”

## Conclusions

Patient advocacy organizations are providing peer support to an incredibly large number of families around the world who are facing the challenges of a rare disease diagnosis. The low prevalence of the conditions categorizes them as “rare;” however, these organizations bring hundreds and thousands of families living with rare conditions together, in person and in social media communities. Despite challenges of funding, strained staff, and the endless quest for information, patient advocacy organizations are providing families in distress with support, resources, and a sense of community.

There is still much work to do, however. Patient advocacy organizations acknowledge the need for a clear, shared definition of peer support services, and are almost universally united in their request for templates and trainings to support the provision of more and higher quality peer support services. The need for collaboration and coordination of these efforts is also widely acknowledged. The landscape must be mapped and simplified, to ease the journey for families.

Physicians and other health care providers have important roles to play in advancing peer support services. Health care providers need education about the needs of the families they serve, the services available in the patient advocacy ecosystem, and the disciplines and science that inform peer support. As peer support gains credibility among health care providers, they become more able to communicate its value to patients and caregivers.

The Child Neurology Foundation has convened a Collaborative Peer Support Workgroup, with representatives of some of the organizations interviewed here, to review this needs assessment and to begin to envision a collaborative way forward. CNF's Family Support and Empowerment Program can be a part of that path.

The FSEP provides a scalable model for the provision of one-on-one virtual peer support. While Peer Support Specialists and the families they serve may have specific conditions or situations in common, that commonality is not part of the FSEP model. FSEP Peer Support Specialists are trained in general principles of peer-to-peer support, and provided resources and staff support to help link families to more specific materials and more targeted organizations, as appropriate.

The needs assessment results spoke of the power of in-person gatherings, and the challenge of providing support specific to the challenges of certain states or particular moments of the journey. FSEP does not currently meet these needs, but may increase the capacity of those organization that seek to

do so, by providing general support to those families currently unserved, and by serving as a conduit through which families can connect to specific communities of which they feel a part.

FSEP can also serve as a locus of peer support training for other patient advocacy organizations; CNF seeks to collaborate with other organizations to develop definitions, expectations, and models for peer support that can be shared across the child neurology community. On this common ground, CNF hopes to build an infrastructure for assessment and improvement of peer support services, and to develop a broader understanding and legitimacy of the role of peer support in advancing the health of children living with neurologic conditions and their families

## Appendix

### Participating Organizations and Acronyms Use in the Text

ALD Connect

Association for Creatine Deficiencies (ACD)

Batten Disease Support & Research Association (BDSRA)

Brain Recovery Project Childhood Epilepsy Surgery Foundation (BRP)

Children's Tumor Foundation (CTF)

Dup15q Alliance

Global Genes

Hereditary Neuropathy Foundation (HNF)

International Alliance for Pediatric Stroke (IAPS)

Lennox-Gastaut Syndrome Foundation (LGSF)

Tuberous Sclerosis Alliance (TS Alliance)

## Interview Instrument

### Interview Guide – CNF PCORI 2018 Initiative

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Interview guide is developed to focus on both individual organizational and community assessment of peer support services, gaps, and opportunities.

#### *Overview to be read:*

In October 2017, the Child Neurology Foundation was awarded a PCORI Tier A grant to establish a collaborative work group aimed at better understanding current peer support practices and needs within the child neurology community. Your participation in this workgroup is very much appreciated and valued.

I (Brad) am the Lead Peer Support Specialist for CNF's Family Support & Empowerment Program. I am joined today by Melissa Capers who will be capturing your responses to these interview questions. When all interviews are finished, Melissa will be developing an Executive Summary to synthesize the findings. Before the Summary is deemed final, CNF will share the draft with you for review and comment.

In terms of the interview structure for today, the first set of questions will focus on your organization's efforts specific to peer support. The second set of questions will explore your assessment of peer support in the child neurology community

For purposes of this interview, the child neurology community includes children and adolescents living with neurologic conditions originating in childhood; their caregivers; health care providers involved in their medical care; social service providers caring for their social needs; advocates; researchers; industry partners; and other individuals engaged in working on behalf of these children/ adolescents and their families.

We estimate this interview will take no longer than 60-minutes. Does that time commitment still work for you?

Thank you. Let's begin.

### Individual Organizational-focused Questions

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1. Please state your name, role and organization you are representing in this interview.
2. Yes/No Question: Does your organization currently offer peer support services? [***If "yes" go to question 4; If "no" go to question 3***]
3. [No: The organization **does not** currently offer peer support services]
  - a. Are you interested in starting a program? [***If "yes", continue; If "no", skip to Community-focused Questions***]
  - b. What do you see as a barrier/s to starting a program?
  - c. What unmet need in your disease community do you think a peer support program would help address?
  - d. What does your organization need to start a support program? [Continue with *the Community-focused questions*].

4. [Yes: The organization **does** currently offer peer support services]
  - a. Please provide an overview of your organization's current peer support services, how do you define peer support? Can you discuss the "how-to" in the provision of support? For example, how are requests handled; face to face vs. virtual, etc.
5. How do peers learn about/ connect to your peer support services?
6. What was your organization's impetus to create/ offer peer support services?
7. What has your organization learned about peer support through these services?
8. What is the biggest challenge to your organization's current efforts?
9. What is your peer support program's greatest strength?
10. Have physicians referred families to your peer support program?
  - a. If yes, how often? Does your organization have an existing relationship with that physician? How do physicians know about your program?
  - b. If not, why do you think physicians are not referring to your peer support program?
11. Describe training & any oversight you give to those in your organization that provide peer support?
12. How do you financially support your peer support services?

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#### Community-focused Questions

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1. How well known do you think peer support is within the child neurology community? [Ask them to expand on this answer.]
2. In your opinion, is peer support perceived as a credible, evidence-based intervention for caregivers living with pediatric neurologic conditions?
  - a. If yes, why?
  - b. If no, why not?
3. Peer support is not a new concept when thinking about family-centered care. In your opinion, what do you think the child neurology community could do to further the provision of it?
4. In your opinion, is peer support more effective when provided face to face or virtually?
5. Are there certain scenarios that you think peer support should be provided face to face rather than virtually? And vice versa?
6. Where do you see opportunities for peer support in the larger child neurology community?
7. Do you think the child neurology community needs guidance on how to provide peer support?
8. Do you think it would make a difference for peer support services if health care providers referred caregivers to your services?
9. What is lacking in the community's provision of peer support?
10. What are funding sources you would consider for supporting broader peer support efforts?