

Subject: February 2018 Resources of the Month

Dear UCCCN members,

Here are your February 2018 resources of the month.

Brainstorming:

Case #1 -- from Pat Rowe, who was able to help overturn a decision made years ago for a child with Prune Belly syndrome who has been admitted many times for “clean outs” using enemas ... SelectHealth wouldn’t pay for some of the items being used off-label. Insurance now supplies and covers everything needed. The mom was very helpful, articulate, knew what she needed, what can be reused, etc., saving them about \$500/mo. Please, tell your families to call Pat Rowe if they need help with SelectHealth insurance. Other insurance: be persistent with your insurance company, present the need clearly, question the status quo. Parents are really the experts - listen to them and be willing to ask questions to fill in the gaps. Ultimately, the parents need to connect with their insurance although care coordinators can help smooth the way. Parents gain valuable skills through the experience, as well, and the child benefits going forward.

Dusty Frisby: Teach parents what language to use, how to talk about their needs, what questions to ask insurance, what they can ask for, so that they can effectively advocate for their child when it really counts. May get coverage as if they’re in-network. Advise them on the appeal process; at the third level, the review board’s physician will appreciate being educated by the parent.

Case #2 -- from Toni Estrada: An update on Vernal family, single out-of-work mom in need of a vehicle for a growing 11 yr old who uses a wheelchair. Active Re-entry provided a van, with a ramp. They also obtained donations to cover tax, registration, and insurance for first 6 months. Family of three is no longer housebound after nearly a year wait. Active Re-entry will convert an existing van, or trade vehicles. Toni worked with Louie Santianez at the Price Active Re-entry. Family is put on a list. Care coordinator needs to advocate repeatedly. Per Gina: in Salt Lake, Davis, Utah counties there’s a lot of need, and funding depends on the Legislative year.

[Services for People with Disabilities](#)

[Active Re-entry Center for Independent Living](#) program which assists individuals with disabilities to achieve or maintain self-sufficient and productive lives in their own communities. USOR Center for Independent Living (CIL) [MHP 11780](#)

Case #3 -- from Tomoko Tsukamoto: Tomoko has been reviewing PCH emergency visits for complex kids. Many families are coming to ED for feeding tube and button issues, largely because practices are telling them to go to the ED. PCH will be creating a Feeding Tube Clinic soon. In the meantime, they can call Tomoko. If patients are coming to the Complex Care clinic, there is a 24 hour number they can call. Families are given emergency G-tube kits. Once used, they need another, may have to pay out of pocket and/or there may be a one-week wait for a rare size. If they don't get another kit in time, they have to go to the ED. Primary care physicians are not comfortable in dealing with G-tubes, G-buttons. Nurses generally administer, and training is needed. Parents can attend a G-J tube class. Tomoko will ask if training classes can be open to professionals. See also the Medical Home Portal's page on [Feeding Tubes and Gastrostomies](#).

Discussion: Healthcare Financial Aid Organizations:

Please note that the list below came from our discussion but is not exhaustive by any means. We encourage you to browse through the service categories (in **bold**) to see more such organizations in the Medical Home Portal's Services Directory.

[Ethnic, Religious, Cultural Support](#) category

[Jewish Family Services](#) Strengthens individuals and families and educates communities through counseling, care management, and community education. [Park City MHP 21740](#), [Salt Lake MHP 10620](#)

[Medical Care Expense Assistance](#) category

[Angel Hands Foundation](#) assists those with special needs with medically related expenses, non-medically necessary equipment, and educational, moral, social support. [MHP 17440](#)

[American Childhood Cancer Organization](#) - [Utah](#) Utah families with childhood cancer. Helps each family cope with life during childhood cancer treatments and rebuild their lives after cancer [MHP 28893](#)

[Children and the Earth](#) Assists Utah children faced with life threatening, sometimes terminal illness, cancer, special needs, rare disease. Financial and material support, wish fulfillment, assists families in fundraising. [MHP 28894](#)

[Millie's Princess Foundation](#) Helps local families with the financial burden of childhood cancer. Two annual parties for children with cancer, the Princess Ball and the Superhero Bash. Contact Ashley Ahlquist [MHP 28892](#)

[Reliance Children's Foundation](#) —financial assistance for terminally and chronically ill children and their families. [MHP 22342](#)

[UnitedHealthcare Children's Foundation](#) Parents of children receiving serious and financially-challenging health care treatment. 16 and under nationwide for medical services not covered or not fully covered by insurance. Cochlear implants and batteries [MHP 13208](#)

Financial Assistance, Other category

[ABLE Differently](#) Promotes a self-help model that serves school and younger-age children and their families with special health care needs, who have not had success with typical forms of intervention. Supports parents solving problems themselves with participation in family-centered community partnerships such as with schools, medical homes, and mental health systems. Some financial assistance for identified need. [MHP 12791](#)

[Gia Nicole Angel Foundation](#) To enhance the daily functioning of a child with special needs and his or her family by awarding assistance through the purchase of a specific item or items; demonstrated financial need. [MHP 28901](#)

[Steelman Family Foundation](#) Raises funding to support families touched by various disabilities, focusing mostly on Cerebral Palsy and Autism, in the following ways: transportation, scholarships, respite care, and caregiver support activities. Partners with Performance Mobility to secure new and used wheelchair van conversions. [MHP 24969](#)

Student Disability Services category (Many school districts have foundations that provide assistance.)

[Davis Education Foundation](#) A nonprofit organization that provides financial support and resources to classrooms, students, and programs within Davis School District. Advocate for "improved educational outcomes." [MHP 10459](#)

[Jordan Education Foundation](#) Engages the community to provide resources, enhance educational experiences, strengthen students, and fuel success in Jordan School District. [MHP 28900](#)

[Weber School Foundation Special Needs Grant](#) Grant funding to foster independence and make education more accessible to Weber County children with special needs. Examples of funded equipment include wheelchairs, speech machines, hearing aids, special chairs, protective helmets, bicycles and iPads. [MHP 28902](#)

Utility Assistance category

[HEAT Program, Utah Division of Housing and Community Development](#) Program provides winter home heating assistance and year-round energy crisis intervention for eligible low-income households. [MHP 11698](#)

Wish Foundations category

[Mascots Miracles Foundation](#) Utah children with serious illness. A nonprofit organization of professional, college and corporate mascots that help children who have a serious illness by creating and attending events, parties, and bringing smiles to those children. [MHP 28892](#)

Disclaimer: These resources come from our members as part of the meeting brainstorming session; please check with your providers to make sure they are appropriate for your patient/families.

You can find a custom list of these service providers that can be printed, emailed, and more, here: [Feb 2018 UCCCN Financial Aid Organizations - Healthcare](#)

Other:

Resources of the Month emails from 2017 have been saved as PDFs and posted with descriptions of cases and presenters here: [UCCCN Resources of the Month](#)

[Harmony Music Therapy](#) Music therapy services to children, adolescents, and adults with disabilities and mental health impairments. [MHP 24911](#) Contact Jaycie Voorhees if you would like any fliers for your practice/office: [801-718-7637](tel:801-718-7637), info@harmonymusictherapy.com www.harmonymusictherapy.com

Our next meeting will be the Spring Learning Session on **Friday, March 23rd, 2018, from 8:30 – 11:30 am** at the University of Utah's Officer's Club. Our topic is **"Care Coordination: What do Families Value?"** Our panels include parents of children with complex, chronic conditions and clinicians in pediatric primary care, sub-specialties and mental health. **Please [register to attend at this link](#) by Friday, March 9th.**

Here is our [UCCCN YouTube Channel Playlist](#) of archived meeting recordings.

Thank you!

Mindy & Tay

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