This Q & A article is from BDSRA’s “Ask An Expert” Facebook Chat in the BDSRA Closed Facebook group for parents and caregivers.

*\*Please note: the information contained in this material is intended to provide basic information to Batten families and caregivers. It is not intended to be, nor is it, medical advice for individual children. Parents and caregivers should consult the patient’s physician prior to changing medication, medical treatment or daily activities.*

“Physical and Occupational Therapy”

Featured Experts:

Danielle Peifer, PT, DPT and Virginia Goddard, MOT, OTR/L

Nationwide Children’s Hospital

August, 2017

1. To start off, could you tell us a little more about yourselves and what you do at PT and OTs
   1. Hi I am Danielle Peifer, a Physical Therapist at Nationwide Children's Hospital that specialized in development in pediatrics, specifically gross motor skills like sitting, crawling, standing and walking. I also work with assisting to prescribe equipment for positioning and adaptive aids.
   2. Hi this is Jeni (Virginia), an occupational therapist at Nationwide Children's Hospital. I address participation and promote independence in activities of daily living (self-care, play, leisure, school, etc). I also help problem-solve positioning and help with obtaining equipment such as bath chairs, activity chairs, and braces for hands.
2. Why is important for a child with Batten disease to see a PT and OT?
   1. A physical therapist can help to determine if a child may benefit from strengthening, stretching, balance training, gait (walking) training, and even positioning at any stage of Battens disease. A PT can also evaluate and determine if any orthotics may be helpful to improve stability when walking, if a device for ambulation may be beneficial such as a gait trainer or walker, and also advice on types of wheelchairs or medical strollers to optimize efficiency and participation in family activities
   2. An occupational therapist can help with maintaining skills that a child has developed prior to regression and can assist with adaptations to promote continued participation in family, school, and community activities. An OT is trained to address visual concerns, need for hand splints, and adaptive equipment for participation of the child and safety for the caregiver for bathing and toileting. An OT can also provide suggestions for positioning in the home environment to promote continued ability for self-feeding or feeding and positioning in the school environment to continue to participate in the classroom. An OT can also assess the use of switches for continued play, as well as, for communication needs. OT can also assist with sensory concerns and behavior concerns.
3. Hi! Could you touch on the proper way to pickup and move our kids? I never am sure if I am picking up and carrying my daughter correctly (for her and me!). She weighs about 43lbs.
   1. From whatever level/height ie bed, chair, floor, etc. you want to remember proper body mechanics including initially inspect your surroundings and get equipment close such as a wheelchair close to the bed or vice versa, etc., get as close to the child as you can, bend your knees rather than forward at your back, hold the child very close, and when transferring to another surface try to turn your entire body instead of just twisting at your back/waist As transfers become more difficult in later stages or as the child gets older/heavier there are options for equipment lifts such as a sliding board or Hoyer lift. If you have two people to assist, one can assist at the upper body and the other can assist the legs.
4. Do you have a life jacket you recommend? Everyone we buy for my 19 yr old seems to go up to her chin and ears once she's in the water.
   1. It depends on what the child's needs are as far as head/trunk control, tone, etc. We have recommended to other populations including cerebral palsy certain ones that can be found at [www.pfd-a.com](http://www.pfd-a.com) They can be very supportive and there are many options available, the Lj-V model goes up to 145 pounds. It will keep you upright in the water rather than floating backward, and also has neck support
5. I was looking at these this morning but they are so pricey I would want to be sure it would work before buying. Do you know any stores that might sell them?
   1. Unfortunately I do not believe that we know of any stores in particular. A lot of swimming equipment are found in catalogs or online we've found. You could attempt to contact this company to see if they are able to send one for loan before purchasing?
6. Do you have any advice about selecting the correct wheel chair for a child with Batten disease? What features should parents look for?
   1. Family, doctors, and therapists need to agree on what the wheelchair will be used for: transport, seated positioning throughout the day, for long distances, etc. It is important to not order a wheelchair through insurance that cannot be adapted as your child grows or the disease progresses. This is because insurance will only approve a wheelchair every 5 years. You should also not choose a power chair over a manual chair if you are unable to transport the chair in your vehicle or get it into your home. You should also be aware of how much space you have to navigate within your home. Most wheelchairs can be adapted and pieces can be changed as needs arise, but a good base that supports your family's lifestyle and expectations is the most important. Another consideration is that obtaining a wheelchair through insurance is a lengthy process and can take anywhere from 6-12 months. So you need to be aware of your child's progression and what that may look like in the future as insurance companies do not like to approve modifications/adaptations on a brand new wheelchair.
7. Do you deal with meltdowns from batten children? How do you handle that if it happens in the middle of therapy?
   1. I would first assess what the triggers may be that are causing the behavior and see if what can be redirected or addressed in a different manner. Depending on the child brief breaks between activities may be warranted with positive reinforcement for what they accomplished. Sensory strategies may also be beneficial as a warm-up to more difficult demands. Each child is different and there may be a period of trial and error while the child and therapist get to know each others personalities and expectations.
8. Do you notice any of our kids having red feet during pt?
   1. Redness in the feet can be common when performing weight bearing actvities including standing and walking due to decreased circulation in children with Battens. As they may not be as mobile on their feet as they previously were and with decreased muscle activity you can get poor circulation. Typically we recommend that if redness goes away after performing these activities within 15-20 minutes than that is a typical response and you shouldn't be alarmed.
9. When is it a good time to start using hand splints?
   1. I am a proponent of not using hand splints unless needed. I typically recommend splints if a child is beginning to develop hand and finger contractures (decreased flexibility with range of motion) and this type of splint would be mainly for positioning for comfort and to decrease progression of contracture. Another time I would recommend a splint is if the child needs extra wrist or thumb support to participate in daily activities.