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.*

**“Navigating Private Insurance”**

Featured Expert:

**Donna Fogle**

Donna is a Batten mom, BDSRA board member, and an Account Executive at The Bailey Group.

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1. Donna, could you tell us a little about your background and what you do with the Bailey Group?
	1. I have been a licensed health insurance agent here in FL for about 13 years. I serve as an advocate for large corporate accounts and try to educate employees about what their benefit package entails, help them get enrolled in the best health plan for their needs and them assist them in navigating the system all throughout the year. I also serve on several legislative panels/ boards both at the state and national levels so I travel often to DC and to Tallahassee to talk with our elected officials to try and get things changed for the better.
2. What are some common problems you see people running into when they are choosing a plan? Particularly for parents of children with special medical needs
	1. Network selection with inadequate provider/doctor access is probably the most common one. Maintaining an established Dr/patient relationship is so important! Too often folks don't take the time to research provider access before they enroll in limited access plans. High deductible health plans ( sometimes referred to as "HSA" plans or consumer driven health plans) often have an aggregated deductible so the family threshold has to be met, not the individual deductible threshold, before traditional co-insurance or co-pays kick in. Also, often the RX coverage applies to the deductible too and that can mean BIG up front out of pocket costs for people. Many people don't know or don't exercise their right to an appeal when a claim has been denied or a prior authorization has not been given. No does not always mean no.
3. What should a family do what they are denied coverage?
	1. Appeal it! Not all insurance carriers, but many have patient advocates/health coaches/chronic care coordinator s who are available to help. Also we agents are here to help too. There are also lots of resources for advocacy through the global genes website too. You can find Global Genes' RARE toolkit on Insurance here <https://globalgenes.org/.../navigating.../introduction/> and their webinar here [https://globalgenes.org/rare-webinar-healthinsurnace101/](https://l.facebook.com/l.php?u=https%3A%2F%2Fglobalgenes.org%2Frare-webinar-healthinsurnace101%2F&h=ATMrFmH0VieZl8cg-c_lYeRoCyj-4tfwmmFUWaCw82QZ6uPgzce2UKplLsshUaID_WRsD_O67POheQEJJ3wjjWCr4vOULuMn7SFA56B38rt0DCMQjHATrxnUTF_BdNTBdppNbqc5) .
4. Other than knowing they have the right to appeal denials what are some things you would like parents to know?
	1. Be an educated consumer. Know what your plans coverage and limitations are. Keep a copy of your plans certificate/summary/SPD. Don't be caught off guard and share that info with your providers. Don't trust that they are going to navigate what is best for you financially, they are trying to do what's best clinically. Sometimes there is a disconnect between the two. Know what you have access to and maximize it. RX is a labyrinth of gigantic proportions!! But remember the story of David & Goliath There are FDA, DEA regulations as well as the carriers own formulary in the equation. (They are modified quarterly too so change in coverage /access is frequent.
5. I'd like to jump in with a question we sometimes get about a specific anti-seizure drug like Onfi. It's often denied to parents whose kids have Batten even though it works well for many and has been around for decades.
	1. I think it's mainly because a prescription of onfi is 1500 a month. We are only allowed 5 prescriptions a month here (unless we fight with a prior authorization or certificate of medical necessity ) so I make sure to always a spot for it. A couple of things may be occurring. There is currently no generic available so plans with generic only coverage will deny. It looks like it will drop off paten in 2018-19 though. The cost for 2.5 mi is $921 and the 20 mi is almost $3500 so there will likely be all kinds of different hurdles to overcome with various carriers to dispense as written. It would not be unusual to also require additional info from the Dr. re: concomitant respitory diagnoses as there are several interaction warnings. It could be an initial no that results in an eventual approvals if the additional steps are taken for Dr. To provide more information. Some plans just may exclude altogether though.
	2. (From Barbara Faulman) Do you qualify? You may be eligible to receive ONFI at no cost if:
		* You do not have prescription drug insurance
		* Your prescription drug insurance does not cover ONFI
		* You are able to demonstrate financial need
		* To find out if you qualify and learn more about the patient assistance program, please call the ONFI Support Center at 1-855-345-6634. <https://www.onfi.com/copay-card-free-trial/patient-assistance#isi>
		* <https://www.onfi.com/copay-card-free-trial>
6. My kids have been denied coverage for physical and speech therapy in the past. We were told that since the outcome of the disease will not change due to therapy they are unnecessary. I am wondering if it is usual for these not be covered? Do you have any advice on getting these services for our boys?
	1. (From Barbara Falkman) Have you been going through the school system to receive services for physical therapy, occupational therapy, speech therapy, etc.? I have also been told that for my two sons that since the outcome of the disease will not change due to therapy or even that therapy is wasting a resource when there is a shortage of therapists in the state or it won't make any difference, so why even bother? (And you don't care how they procure the therapist, they do have to find one ---even it is by subcontracting through a home health agency, hospital out-patient unit, independent therapist, etc.) Disagree with their recommendations. Disagree and request an individual educational evaluation at public expense. My children received tons of therapies in school, including OT, PT, orientation and mobility (O and M) instructor, teacher of the visually impaired, speech therapist, assistive technology, augmentative communication, nursing services etc. in school. You have to become very familiar with the protections and due process rights in your school system and in your state special education regulations. And you have to switch gears to IDEA, Part B and use their related services definition and explanations in your language when speaking and requesting anything. The related services are necessary for your child to attend school---comfortably, safely and with peers. Thinking of both of you and your families. <http://www.parentcenterhub.org/repos.../iep-relatedservices/>
	2. (Donna Fogle) Often there is the requirement that the physician supply more information in order for certain high dollar medications to be covered right off the get go. They have to justify that other less costly options have been explored before they approve. Especially the new meds as the efficacy still may not have met their approval. The manufacturer as well as the physician can also usually assist with the initial dose while the approval process in occurring. Typically certain services are contingent upon the diagnosis that they are being ordered for. I've always heard that physicians need to "code to the highest level of specificity" meaning that although Batten may be the primary blanket diagnosis, PT should be ordered with a diagnosis of joint contractures or muscle atrophy or something more specific to get the CPT codes to match the Diagnosis codes.
	3. Thank you, Donna for mentioning about CPT codes. For parents who have a child with Batten Disease, there is a medical diagnosis and diagnosis code for Batten Disease disorder itself. Remember that all of the therapies such as physical therapy, speech therapy, occupational therapy, etc. are services that are medically necessary and the services are accessed through private health insurance, Medicaid, Medicaid waivers, private pay and through the school as educationally related services (under IDEA Part B and Part C) from ages birth to 21 years of age. When a child has Batten Disease and has difficulty in walking, or with gross motor skills for example, the physical therapist will evaluate the functioning of gross mtor skills, and the child will receive services because of the gross motor skill deficit and not because the child has Batten Disease. The CPT stands for current procedural terminology and that speaks to how the physical therapist is going to address the gross motor skill deficit area during therapy, and what the therapist will be working on when billing for services. CPT codes are used to describe tests, surgeries, evaluations, and any other medical procedure performed by a healthcare provider on a patient and report to entities such as physicians, health insurance companies and accreditation organizations. <https://www.webpt.com/blog/post/farewell-97001-how-to-use-the-new-pt-and-ot-evaluation-codes>