

Guide for Daily Living with BCAP31-related disorder

This is the 'guidebook' I wish I'd had during the first several years of navigating life with Alan after his diagnosis. The list of doctors, specialists, therapists, equipment, medication, insurance paperwork, etc is enough to overwhelm any parent, so while this information is certainly not exhaustive or representative of every patient's experience, I hope it is helpful to at least help get you oriented to a plan of care. It takes a village!

- **Doctors**

Alan's medical team includes the following specialists:

- Allergy Immunology → management of severe seasonal allergies
- Audiology → cochlear implant administration & maintenance
- Gastroenterology → g-tube administration & maintenance; nutrition
- Genetics → seen ~yearly; communicate ad hoc re: research opportunities
- Neurology → seen ~ yearly; a critical point-person for any advanced care/specialist needs
- Ophthalmology → annual exams to monitor optic atrophy & oculomotor apraxia
- Pediatrics → has scheduled check-ups every 6 months (in addition to as needed)
- Physiatry → specialized clinic providing 'one-stop-shop' for several of his specialists & therapists; we use this clinic to get fitted & approved for all of his equipment

- **Therapists // Educational Supports**

- Physical Therapy → 6x/month
- Occupational Therapy → 6x/month
- Speech/Communication Therapy → 1x/week
- Deaf & Hard of Hearing Specialist Teacher → 1x/week
- Special Education Teacher → 1x/week
- Therapeutic Horseback Riding → 1x/week

- **Equipment**

- Wheelchair → TLite Twist
- Activity Chair → Rifton Hi/Lo

- Seated Bath Chair → Firefly Splashy
 - Shower & Toileting Chair → Rifton HTS Hygiene & Toileting System
 - Specialized Car Seat → THOMASHILFEN Hercules Prime Booster
 - Ankle Foot Orthoses (AFOs) → Cascade DAFO
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- **Medications**
 - Miralax → daily dose for constipation; administered by feeding tube
 - CoQ10 supplement → 3x/daily for cellular function; administered by feeding tube
 - Clonidine → given as needed at night for occasional sleeplessness/night wakings
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- **Insurance**
 - Medicaid → Alan had private insurance & Medicaid for several years but we have now streamlined to just Medicaid coverage. It has simplified paperwork and it covers everything we need it to. The application paperwork can be tedious but it's so worth the time investment! If you have specific questions, please reach out.
 - Community Alternatives Program for Children (NC) Waiver aka CAP-C → this has different names in different states (e.g. Home & Community- Based Services for Developmentally Disabled in California). This is a Medicaid supplement that covers specialized equipment, reimbursement funds for home & vehicle modifications, 1:1 aide services and more. The application process is long and tedious but the dividend is huge! You also get a dedicated case manager to help navigate and administer all of the benefits that the waiver covers.
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- **Miscellaneous**
 - [The Miracle League](#) → adapted sports leagues for children with significant disabilities
 - [Accessible Adventures Community](#) → Facebook group for parents who are planning inclusive travel and adventures for their families
 - [A Kid Again](#) → offers free local events and activities for families who have a child facing a life-threatening condition
 - [Team Impact](#) → matches children facing serious illness and disability with college sports teams, creating a long-term, life-changing experience for everyone