

Care Coordination – tracking information 6/6/10

Region 4 parents were asked: Thinking about your role as a parent of a child with a genetic condition, what information have you found helpful to track? (For example, medical expenses, diet, medications, physicians or any and all things you can think of!)

12 parents responded

MEDICAL

Contact information for doctors

- Updated and current list of her doctors with fax #s, emails, etc. (when she turned 18, I had her sign the bottom to give everyone permission to talk with everyone else)
- Phone numbers/contacts of all physicians/dentists

Medical History

- A medical history list with the name of her condition, date of birth, address, surgeries and dates, allergies
- Number of illnesses and what they were AND how they were treated (they always ask that at yearly visits)

Medical Appointments

- List of recent doctor appointments and their results as well as upcoming doctor appointments so labs/other info can be coordinated.
- Specialty visits
- Appointments scheduled – doctors and dentists
- Number of doctor appointments and with which type of doctor

Labs/Tests/Procedures

- Echo, and MRI and other test results
- Lab work (3 people reported tracking this)
- Procedures/surgeries

Medication

- Medication (7 people reported tracking this), also changes in medication doses and the reasons they were adjusted/changed
- When I order medications I track who I call, who I talk to, everything they say...then I have to document when I paid, how I paid...otherwise our mail order pharmacy tries to come back and say that things weren't done as they actually were.

Emergency

- Emergency information to give out including doctor names and phone numbers, allergies and insurance info typed up and what to do if there is a problem and what a problem looks like.
- Emergency contact info for me and my husband (at age 18 we added a medical release for everyone to talk to my husband and myself)

Other Medical

- Weight
- Scheduling of nurses/respite
- Therapy reports

SCHOOL

- IEP (3 people reported tracking this)
- Logs of communications with therapists and specialists
- Samples of work from every grade.
- Performance at school
- Medication administration at school

INSURANCE/TAXES

Insurance

- Insurance binder – all claim forms, logs of conversations, copies of bills and payments, reimbursements from medical spending, etc.
- Explanation of Benefits (EOB) from insurance (2 people reported tracking this)
- Insurance materials and receipts (2 people reported tracking this)
- Insurance policies up to date and paid for on a timely basis
- Insurance info and policy #s

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Expenses

- Medical receipts for tax purposes (3 people reported tracking this)
- Medical expenses (2 people reported tracking this)
- Receipts for Flexible Spending Accounts

Other Insurance/Expenses

- Mileage for appointments and hospital stays

MEDICAL FOODS/FORMULAS & DIET

Diet Tracking

- Diet (5 people reported tracking this)
- Eating habits
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Food and Formula

- Formula recipes for measuring appropriately
- Formula supplies (ie, tubes, syringes, formula) are ordered and delivered on time
- Medical food/formula sources – catalogs or price lists, copies of invoices, my customer #s, etc.
- Current list of formulas and supplements

MISC.

- Research info – on new research, contacts, emails from other families
- Work-related salary information that will be needed to send to Social Security and/or State Medical Assistance for qualification purposes
- Personal care attendance hours allocated and use appropriately
- Guardianship paperwork up to date and keep track of all papers related to this
- The social calendar!