

BEING YOUR CHILD'S ADVOCATE

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What Is An Advocate?

- One that argues for a cause; a **supporter** or defender (American Heritage Dictionary)
 - One that pleads in another's behalf; an intercessor (American Heritage Dictionary)
 - An advocate supports, helps, assists and aids (Merriam-Webster Dictionary)
 - A synonym for advocate is support
- Who is a natural advocate for a child with Galactosemia?

Interesting Research

- Researchers studied the childhoods of 400 of the most creative, gifted and talented people (Einstein, Schweitzer, Gandhi, Roosevelt, Churchill, Edison, etc.) and found $\frac{3}{4}$ of them had tremendous handicaps in life
- What helped them compensate for the handicap is a "significant someone" who helped him recognize a hidden talent and encouraged it's development
- They all had an ADVOCATE!

6 Skills to be an Effective Advocate

- Become Informed
- Learn the Rules of the Game
- Plan and Prepare
- Ask Questions/Identify Problems / Look for Solutions
- **INVOLVE YOUR CHILD**
- Take Care of Yourself

Becoming Informed

- Thank God for the INTERNET...USE IT
- Research whatever problem is at hand (Galactosemia, learning issues, speech issues, etc.)
- Talk to others who may be experiencing a similar issue
- Attend educational meetings, conferences, etc.
- Sign up for newsletters
- Keep current with websites that can help you
- Questions to ask
 - What causes the problem?
 - What can I do about it (treatments, therapies)?
 - How did you become educated about xyz?

Learn the Rules of the Game

- Know how the system works
 - * What is each person's role and responsibility at doc's office, school, day care, etc.
 - * Is there someone at the office that will help you with insurance? Does your company have HR people that will help if something is denied?
- Know your rights
 - * If there is an educational issue consult the Individuals with Disabilities Education Act (learn about IEP's and 504 Plans)
 - * If there is an issue related to a disability consult the American's with Disabilities Act

Learn the Rules of the Game

- Questions to ask
 - * If I have questions at home who is the best person from the office to contact
 - * Should I call or e-mail (get #'s, etc.)
 - * Ask for standards of care, rules, systems in writing. If there isn't one ask your doc, school, etc. to create one for you
 - * Ask who is in charge of what areas? Who makes the decisions about xyz?

Example Standard of Care for Children with Galactosemia

This is an **EXAMPLE** of information I gathered from my son's doctor. This is **NOT** an approved or official standard of care being endorsed by the Galactosemia Foundation. Ask your doctor's office to prepare something like this for you and your family.

6 months - 3 years of age

Doctor's visit every 6 months (or as needed) including:

Medical exam

Psychological Exam (6m., 1 year, every 2 years after that)

Social Screen (6mo., 1 year, then every 2 years after that)

Labs

Gal-1-P (blood test)

Galactitol (urine test)

Vitamin D level (blood test)

Girls only labs (2 years old and 12 years old)

LSH

FSH

Eye exam starting at 6 months every 1-2 years

3 years of age and up

Medical exam and labs 1x a year

6 years old

Dexa Scan (bone density)

Plan, Prepare, and Be Organized

- Go to your child's doctor visit, school meeting, etc. like you are going to a business meeting
- Think about what you want to say and ask.....WRITE IT DOWN
- Keep a binder of your child's information (last test results, last meetings notes, insurance info.etc.)
- Keep Written Records - write down phone conversations (date, who spoke to, etc.)
- Print e-mails

Ask Questions/ Identify Problems/ Look for Solutions

- Don't be afraid to ask questions until you understand the answers
- Ask for written responses so you can refer back
- Write down any problems that are occurring or you foresee and bring them up at appointments/meetings
- You know the old saying, "If you're not part of the solution, you are part of the problem." Be part of the solution...no one will be more interested in finding an answer to your problem than YOU

Involve Your Child

- Give realistic and understandable info. to child about galactosemia, diet, learning issue, speech, etc.
- Treat the diet and other therapies as matter-of-fact
- Don't undervalue or overvalue galactosemia
- Teach positive attitudes about differentness
- Teach your child to be in charge of his/her own diet

Involve Your Child

Children with Galactosemia need:

- Self confidence about abilities
- To feel loved and accepted
- To have a healthy self-esteem
- To view self as competent and productive
- To know how to deal with questions from peers and other "sticky" situations
- To know how to problem solve

Involve Your Child

- Take the shame out of “being on a different diet”

“Dietitians and physicians have routinely observed dietary efforts fail more often from psychological factors than from nutritional factors”

“One reason... children’s [medical] diets falter is that ..parents have not achieved acceptance of the medical condition..”

Why Can't I Eat That, John F. Taylor/ R. Sharon Latta

Involve Your Child

- We teach our kids how to feel about themselves and their situation
- Make sure your words, looks and body language say,

“You can do this. It’s part of life. It won’t hold you back”

NOT

“This is sad. I feel sorry for you. This is hard.”

Take Care of Yourself

- Know how you feel and how it will affect your child
- Common emotions of parents of children with disorders
 - * Denial = minimizing
 - * Fear = worry, anxiety, no action
 - * Anger = mishandled leads to big issues, leaks out in other areas of life
 - * Guilt = assuming personal responsibility
 - * Overinvolvement = overprotection, spoiling, pity and nagging

Take Care of Self

- If your emotions are extreme or hard to control GET HELP
- Get enough sleep
- Eat right/ exercise
- Find a way to enjoy life
- Find a healthy outlet
 - * Working out
 - * Reading
 - * Coffee with a friend
 - * Crafting
 - * Fishing

Tips to make restricted diet easier

- Plan meals and snacks
- Keep shelf in pantry/refrigerator for G. kids snacks so he/she can serve self
- Make ahead and freeze individual servings of favorite foods
- Know what is safe at a restaurant before you leave home
- Make it a habit of carrying safe foods with you

Being an advocate at a Restaurant

- Be careful of your words. Instead of "my child has a disease" or "my child is sick" use "we have special dietary needs in our party, can I speak to someone about ingredients and preparation?"
- Use kindness
- Explain only the necessities
- Ask again when the food is delivered, "So just to clarify, this is a burger cooked without butter and these veggies were steamed with nothing added?"

Resources

Office of Special Education and Rehabilitation Services
US Department of Education
400 Maryland Ave. S.W.
Washington, D.C. 20202-7100
202-245-7468

American's with Disabilities Act
1-800-514-0301
ADA.gov
