Nothing is more heartbreaking for parents than receiving the label of “autism” for their beloved child. Hopes and dreams for a child never include this devastating diagnosis. As follow-up appointments come and go, many families, including mine, have heard this statement from professionals: “There is nothing you can do.”

Parents of newly diagnosed children are bewildered, because many children on the spectrum have medical symptoms that are not explained by an autism diagnosis. The child’s doctors, who typically do not look beyond the autism label, rarely address these symptoms, including gut problems, allergies, rashes and others.

In the new millennium, in which doctors are capable of saving thousands of lives using state-of-the-art treatments, the evaluation and treatment of autism appears to be trapped in the Dark Ages. While much progress has been made in the past 20 years through the use of traditional therapies, including applied behavioral analysis (ABA), speech therapy, occupational therapy and other key therapies, little has been offered in the way of biomedical intervention and treatments for children on the autism spectrum. This is even more frustrating now that we are in the midst of an epidemic affecting one in 166 children.

There is good news, however. What I can share with parents of newly diagnosed children, and with families who have been on their autism journey for a while, is the knowledge that there are effective treatments—and there is hope.

Talk About Curing Autism (TACA) includes more than 2,100 families, many of which are exploring biomedical and alternative treatments. More than 40 TACA families have recovered children (meaning the child’s diagnosis is no longer germane and they are indistinguishable from their peers), and more children are well on their way to recovery.
These successes are due to a combination of biomedical interventions and traditional therapies.

In many cases, families want to treat their children’s medical issues, which can include lack of sleep or severe sleep disturbances; extreme gut disorders (often including alternating diarrhea and constipation); rare parasites, viruses, yeast overgrowth or bacteria; extreme allergies to foods or substances in the environment; unexplained rashes; swallowed complexions; dark circles under the eyes; and behaviors that ebb and flow in patterns that may coincide with physical symptoms.

Most parents partner with knowledgeable and open-minded physicians to explore treatments that will address both the behavioral problems and the physical symptoms of their children. As key members of the treatment team, these parents play an important role in working with a variety of medical professionals.

The first and most crucial role parents have is selecting the medical team that will guide their child’s treatment plan. In making this decision, it is important to understand that many doctors follow the guidelines of the American Academy of Pediatrics (www.tacanow.com/pdf/33%20-%20aap%20standards.pdf). These guidelines, which have not been updated since May 2001, discourage physicians from recommending the cutting-edge treatments that help many children with autism spectrum disorders because these approaches are considered “alternative.”

This point is extremely important, because if a test or treatment is not recommended in the standards of care, the costs for testing and treating may be left up to the families. In addition, the professionals who work with our special children need to think “outside the box” to address children’s biomedical symptoms and issues.

Selecting the right physician is just the first step that parents need to take in the journey toward a better life or even a full recovery for their child. The insight of parents is crucial in providing valuable clues about treatment priority, and providing this insight in a knowledgeable and organized manner can optimize treatment for the child with autism and save money, time and effort for families.

Following are the key steps parents can take as they participate in this medical treatment process:

I. Read. Parents need to read both books and information on Internet sites to prepare for their role in the treatment process. TACA offers the following online articles:

- “Why are DAN! (Defeat Autism Now!) Doctors So Expensive?” This site includes tips and tricks to prepare for medical appointments and testing: www.tacanow.com/dan_docs_expensive.htm.
- “What is it? When Something is Going On; Strange Behaviors, a Plateau, an Old Self Stims.” This site provides a troubleshooting checklist for families in the biomedical process: www.tacanow.com/whatisit.htm.

Among the books that parents have found most helpful when beginning treatment are:

- Unraveling the Mystery of Autism and Pervasive Developmental Disorder, by Karyn Seroussi
- Evidence of Harm, by David Kirby
- Is This Your Child? Discovering and Treating Unrecognized Allergies in Children and Adults, by Dr. Doris J. Rapp
- Autism: Effective Biomedical Treatments (Have We Done Everything We Can For This Child? Individuality In An Epidemic), by Dr. Sidney Baker and Dr. Jon Pangborn
- What Your Doctor May Not Tell You About Children’s Vaccinations, by Dr Stephanie Cave, with Deborah Mitchell
- Additional Web resources pertaining to biomedical treatments include:
  2. Thoughtful House – www.thoughtfulhouse.org
  4. TACA www.tacanow.org (parent-to-parent information)

II. Get Educated. Attend a Defeat Autism Now! (DAN!) conference for the latest in medical research and information. For a listing of upcoming events, visit www.danconference.com.

III. Network. Talk to multiple families about the most recommended resources. Even though children with autism spectrum disorders have different needs and require individualized treatment protocols, input from other parents can be invaluable in providing reviews of resources, stories about successes or failures, and tips that could save time and money.

IV. Select a Partner You Like for the Long Haul. Interview several doctors before you choose one as your treatment partner. Since you will be working with this professional on a regular basis, it is good to pick someone you like and can communicate with effectively.

V. Document. Parents should document their child’s history carefully so that they can give their doctor a complete record. It also is helpful to write a one- to two-page summary—a “Cliff’s Notes” version of the child’s file—that hits such high points as regression information, current medical therapies and traditional therapies, and key issues that need to be addressed. Copies of
recent behavioral or psychological assessments and the IEP (Individualized Education Plan) from the school district also will yield important clues for the doctor.

VI. Prioritize. Prioritize your child’s issues when you address them with the physician. If your family is getting little sleep or your child has gut issues, these often are good places to start building a foundation for overall health. Then identify other issues that need attention. Your input is important in setting priorities so the doctor knows what should be the focus.

VII. Evaluate Costs. Take the guesswork out of this important question and find out. While costs may vary according to each child’s unique medical issues, it is important to outline fees in advance for office visits (typically one to three per year), emergency/after-hours calls, phone consults, treatment protocols, lab fees and other items. Obtaining insurance pre-approvals for treatments also can be a lifesaver for the family wallet.

VIII. Emergencies. If a treatment causes side effects, parents should obtain clear guidelines as to whether they should call the doctor or emergency facilities. A description of non-serious side effects (continue the treatment) versus serious side effects (stop the treatment and/or call the doctor’s office) should be clearly provided at the end of each appointment when starting a new treatment protocol.

IX. Read Some More. The education process will continue after your first year. It is especially important to read about each suggested treatment after a doctor recommends it and before you try it on your child. Research and information are rapidly changing in the medical treatment field and continuing your education is a necessity.

X. Evaluate Treatments. The treating professional should outline the positive and negative results a treatment could yield. Creating an easy-to-use “check-off” document outlining each day’s treatment is extremely important in this process. This should include the following data: meals, bowel movements, liquids, medication, sleep patterns and behavior changes. Keep your daily journal in an easy-to-find place where you will see it and can easily jot down notes. Bring the journal on follow-up doctor appointments or have it handy during phone consults.

A Few Warnings. In the biomedical journey, a few words of caution are warranted:

1. Not These Words! Don’t let the diagnosis of autism be an excuse for failing to treat issues that are medically necessary to treat. If a doctor says that a medical issue is “just part of the syndrome,” it may be time to find a new resource.

2. How Long? Don’t give up if you try only one or two treatments and they do not help your child. It’s heartbreaking when I hear parents describe how the failure of a treatment led them to stop biomedical intervention altogether. Children on the autism spectrum are unique. The solutions to their medical problems are unique as well, and answers are still emerging. It is important to remember that the biomedical intervention process can take a long time to yield results, but these results can be amazing, if you use patience, a good doctor and medical test results to help design a treatment plan unique to your child’s needs.

3. Charlatans. As in any growth industry there are sales people ready to sell you products, including medical treatments for your child. Work with your doctor and parent community to identify treatments for your child and verify good resources to use.

4. Trust Your Instincts. If something about a situation or office or medical professional does not feel right, it may not be. Do more research on the provider and ask other parents for feedback. It is important that parents never lose faith in their instincts in this process.

Some Final Words: Selecting Treatments. Medical treatments for children on the spectrum should be selected based on family history and patient intake (symptoms and history). Medical test results (current and past) also provide important markers.

Doctors should look at what the child has responded to, both positively and negatively. This information will yield important clues when it comes to selecting treatments unique to the child’s needs.

Finally, based on the parent/child issues, doctors should:

• be able to set treatment priorities
• allow the parents to prioritize these treatments as a team

Biomedical treatment should be a key part of the intervention plan for a child with autism. In addition, consider one-on-one behavioral intervention, including applied behavioral analysis, verbal behavioral analysis, speech therapy, occupational therapy, and therapies to address play skills and social skills. Combining biomedical intervention and intensive one-on-one therapies can offer a comprehensive treatment approach for a child affected by autism.

AUTHOR
Lisa Ackerman is a parent whose experience includes one child: her son, Jeff. She has quit her job in management to work full time with her son and other families through a group she founded, Talk About Curing Autism (TACA). TACA started with 10 families in November 2000, and by August 2006 had more than 2,100 families and seven meeting locations in California. For more information about TACA, go to www.tacanow.org. Ackerman also does a bimonthly free online radio show at www.autismone.org/radio.