

Sam & Sue



I'm the mother of and care provider for my only son, Sam, who is chronically ill with life-threatening allergies, Asthma, Herpes and Severe Chronic Atopic Eczema. Our Pediatrician said he did not have time to take on a complicated case like Sam's. He only wanted to treat Sam for simple things like immunizations, ear aches or sprains.

He said, "I don't have time to read up on your child's condition. They don't pay me enough to spend that kind of time on one patient. I'm sorry. I don't have time to coordinate a team of five physicians to give your child the care he needs. You may want to find another doctor."

When he said that, I just wanted to cry. I thought, 'how am I supposed to find a doctor who is willing to take on my child's rare and complicated case? I am providing around-the-clock-care to a very sick little boy and now I have to search for a generous doctor, too.'

However, I didn't have time to feel sorry for myself. Sam's pediatrician said I needed to find someone to coordinate Sam's health care team of specialty doctors. We were seeing the dermatologist 3 to 4 times a week for UV treatments so he seemed the logical choice.

At the next dermatology appointment, I asked Dr. Smith, Sam's dermatologist, who he would recommend to lead Sam's medical team. He said "Oh, I'll do it, no problem." It was just that easy. All I had to do was ask.

How did I find such a great dermatologist?

Very quietly, I asked receptionists and nurses at 5 other offices who they would recommend. Someone with a kid-friendly personality who would treat us with respect. The same name came up over and over. It was Dr. Smith.

Talk about **Accessibility!** His office is only 5 miles from our house. He accepts my insurance. His home phone number is in the telephone book. I only called him at home one time during an emergency. He gave me his cell phone number after Sam was diagnosed with Herpes because Sam will need immediate treatment if the herpes get in his eyes. Dr. Smith's 2 nurses are empowered to find medical care for Sam when Dr. Smith is on vacation. His nurses return phone calls the same day. One of the benefits of this Medical Home is that we regularly see the same PCP (Primary Care Physician) and the staff know us by name.

How is this practice **Family Centered**? Dr. Smith never talks down to me the way the Allergy doctor does. I am respected as an expert on Sam's skin care. He knows that we value being able to swim in the Lake 2 times per year and that means Sam will need an antibiotic because he will get infected. The doctor never forbids us from that swim because he knows it is important for Sam to feel "normal," sometimes even at the expense of a bacterial infection.

As an expert on the team, I can request trying a new moisturizer when I think it's needed. Dr. Smith even asked, "How well are all of you sleeping?" He realized that Sam's extreme itchy and raw skin was worse at night and kept my husband and me awake on alternate nights, rocking a screaming and crying child.

Every year before school starts, his office reviews the 5 medication permission forms and signs them. His office staff even remove the Glade plug-ins on the days Sam has a doctor's appointment. The air fresheners will set off a really bad itchy spell if left in place.

How is **Continuous Care** provided? Dr. Smith reviewed our insurance list of family practice providers and helped us transition from a pediatrician to a family practice doctor. We felt supported in finding a new PCP.

What about **Comprehensive Care**? Dr. Smith has briefed all the doctors on call about Sam's condition. Someone who knows all about Sam is available 24/7.

We even have a preventive game plan in place for ER visits. We know to call Dr. Smith on the way to the hospital so the ER doctors are not overwhelmed by Sam's complicated case. We had a strained ER visit once for a broken bone because the physicians were afraid of Sam's eroded skin and itchiness.

To further illustrate comprehensive care, I need to mention the special team our Dentist put together for Sam. Our Dentist held a brunch and invited the Orthodontist and Maxofacial surgeon. They discussed all of



Sam's allergies and special needs and created a long-term plan of treatment.

The orthodontist's office even has a patient liaison, Miss Jane. She reviewed Sam's orthodontic treatment plan and had him sign a patient agreement that he would do his part to make treatment successful. She told me my job as the Mom was to bring Sam to appointments and to pay the bill, period. I found it necessary to call Miss Jane when Sam and I encountered a rude and hostile dental technician in their office. The technician received more training and the orthodontist called me at home to apologize for the rude care we received from his technician. The ideal medical home model includes a patient liaison.

How is **Coordinated Care** provided? One technique we use to make sure everyone on the Team has Sam's current information is to utilize a USB Flash Drive for easy portability of Sam's entire medical record. Ask your doctor about using this method.



Our coordinated plan of care is called **The Current Treatment Plan** (see Sam's Medical Notebook [next page])). This is carried to all doctor visits and each doctor photocopies it for Sam's medical file.

Sam's dermatologist also cares about Sam's psycho-social needs. He sent Sam to Skin Camp 3 summers. It was paid for by the American Dermatological Society. For 3 glorious weeks, Sam felt like a typical kid instead of "monster boy," which is what he was called at school. Dr. Smith reads and investigates the latest pharmaceutical publications for new treatments like Elidel.

He advocates for Sam by writing letters to the school nurse to let staff know that Sam has eczema, not infectious impetigo. Dr. Smith also writes letters to the custodians asking they not use weed or bug spray near Sam's compromised skin. The coordinated care we receive helps us feel connected to new information and support organizations like skin camp.



Dr. Smith provided **Compassionate Care** to our family when we received the Herpes Simplex diagnosis. Herpes is like having cold sores but it's all over Sam's body. I cried, and Dr. Smith put his hand on my shoulder and said "We'll get through this together. You're not alone." He encourages Sam at every visit by saying "We're gonna fix you up kiddo." Compassionate care provides hope and promotes our mental health.

No barriers to **culturally effective care** exist with Dr. Smith. There is no language barrier. We trust each other. He does not stereotype by race, sex or class. In addition, the doctor knows that at Christmas and Easter, Sam will go off his special diet and a skin infection will result. Dr. Smith never shames us or insists on Sam staying on the diet. He simply says, "Let's plan for an antibiotic and good wound care following the holiday meal." The benefit of the culturally effective care is that it promotes Sam's quality of life. He gets to have a holiday with holiday foods like typical children.

What is Sam's life like today? Today, at age 16, he is thriving! Puberty transformed his immune system by calming it down, just as the doctor predicted. His olive complexion masks much of the skin scarring. Sam not only looks normal, but also, the girls find him simply dreamy. He has long ringlets of soft brown hair down to his shoulders.

He still has food and nasal allergies and occasionally, asthma. Sam will probably have to remain on daily Valtrex for the rest of his life because of the Herpes Simplex One complication from his childhood eczema. He says, "All things considered, 'life is good.'" He is taking all honors classes with hopes of becoming an engineer just like his Dad.

His favorite thing to do these days is to play soccer for two teams. Sam says, "Most people take for granted what it is like to be a regular, typical, normal person. I'm so glad people don't stare at me anymore just because of my skin. Now when a girl looks at me, I think, "She's checking me out...sweet!"

Sam has a lot more free time now that he does not have to see two or three doctors every week. He's down to one medication check every three months with his dermatologist and his allergy doctor.

Our Medical Home Partnership yielded a safe holding environment that brought us through the pit of despair into the light of hope for a future. Our Medical Home doctor held the hope when we could not. This emotional support was priceless. In addition, our Medical Home doctor was easily accessible for consultation when Sam had emergencies like fractures and ER visits. This avoided the frustration of educating ER doctors about Sam's complicated case. Moreover, it provided a buffer



with Child Protective Services when the ER doctors' fears caused them to think that I was either abusive or had Munchausen's-by-Proxy.

Furthermore, the MH doctor coordinated Sam's medications among his team of five specialty physicians. This provided the safe assurance that Sam would not have drug interactions since he was on numerous prescriptions and supplements.

Through our MH doctor, Sam has experienced what is like to work in partnership, and what it is like to be treated with respect by a doctor. Sam has learned through experience that doctors are not deities (gods) who control your choice of medical care. Overall Sam has learned to partner with his MH doctor and use him as a knowledgeable consultant on our team. ♥



Note: although this is a true story; the names of the individuals have been changed to maintain their anonymity.

Sue's Tips for Finding a Medical Home

- ★ Ask your current Primary Care Physician (PCP) who they refer patients to see.
- ★ [Quietly] Show a list of insurance-approved providers to receptionists, secretaries or nurses at your PCP or specialty care doctors' offices. Ask who they think is **friendly, accepting, and easy to work with**.
- ★ Ask friends who they would recommend.
- ★ Call offices that are highly recommended.
- ★ Decide whether a clinical setting or a private practice meets your family's needs best.
- ★ Schedule a get-acquainted appointment with the doctor.
- ★ Use the Medical Home checklist as a prompt for questions for the doctor and staff.
- ★ Prepare a list of questions for the appointment.
- ★ Write down the name of each staff member you meet: receptionist, nurse and secretary.
- ★ Does the doctor remind you of your least favorite relative? What is your "gut" feeling? Can you trust and work with this doctor? Does your child like the doctor and nurse? ♥

Sue's Tips for Maintaining a Medical Home

- ★ It is helpful to have respectful interactions with all members on the team. Remind yourself that you need each member on your child's team.
- ★ Ask about office procedure. "What's the best way to get ___'s school medicine papers filled out and signed?" How will you know when they are ready to pick up? Will they call you or should you check back in a few days?
- ★ Call the doctor after hours only when it is urgent; don't abuse the privilege. Some doctors have been known to provide their cell and home numbers. Ahead of time, discuss with your doctor which issues warrant an urgent call.
- ★ Send thank you notes for service beyond the call of duty.
- ★ Once a year, when possible, I give small, tasteful, inexpensive appreciation gifts to each staff person and doctor. (small potted plants, chocolate, homemade bread) I always include a heartfelt note of appreciation. ♥

Sam's Medical Notebook Table of Contents

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| ★ Current Treatment Plan | ★ Prescriptions chart (when and what to refill) |
| ★ Emergency Information form | ★ School Authorization for Medication forms |
| ★ Health history overview/diagnoses | ★ Pocket for photos, if appropriate |
| ★ A list of team of physicians and phone numbers | ★ Alternative medicine Information |
| ★ Dates and names of surgeries, fractures & treating physician | ★ Daily Medicine & Progress Charts |
| ★ Medications, by drug, year, diagnosis and reactions, if any | ★ Pocket of blank charts ♥ |
| ★ Business cards of doctors, counselor, PT, and OT | |