

### **COMMENTARY**

#### **Let's work together**

Charles H. Spencer

Collaboration and cooperation between distant institutions and organizations nationally and internationally happens all the time and may improve even more with the efforts of PRINTO and CARRA. But local and regional cooperation is an equally, if not more important issue.. It is often harder to work together in urban areas and regions where several centers share the same patient catchments. Yet this collaborative and cooperative effort is just as important as our national and international efforts.

This goal is often challenging and requires attention to practice habits: 1) competition for patients especially using marketing; 2) providing second opinions; 3) recruiting patients with certain diseases aggressively for research purposes; 4) trying to corner patients with one disease in any one area; 5) emphasizing elite institutions or Mecca's over the average pediatric rheumatology center. These issues are all interrelated and bear some examination and discussion.

#### **Competition for patients and marketing**

With our zero-sum background, it's natural for us to enter into a competitive mode in large urban areas that may be decentralized and balkanized by several pediatric medical systems and insurance programs. Plus we may feel that our center, and we in particular, do it best, whatever it is. I am convinced that for the next 20-30 years, there are more than enough patients for everyone in most countries and we should trust that other centers, and each of our colleagues in these centers, can do just as well with patients as we do. When you have a patient move to your center from another and you look askance at the treatment received, remember that you are seeing the numerator but have no idea of the denominator. How many patients have been treated at that center and done well with that treatment approach that we don't favor? Is the treatment issue in question evidence based? Maybe it is, but often not. We should be generous and tolerant. There is plenty of business for us all.

#### **Providing second opinion consultations**

We all are likely to be familiar with this academic consultation behavior. A patient of pediatric rheumatologist #1 (PR#1) goes to another center for a consult, either referred for a second opinion (parents' or doctor's idea or both) or going on their own by word or mouth or online marketing. The pediatric rheumatology consultant (PR#2) criticizes the original center and physician's medical care. The criticism can be just as much in what is not said as in what is said. The parent transfers the child's care to the new center. The parent says that they are only interested in what's best for his/her child. PR#2 justifies their behavior by his/her belief that he/she knows best for the patient and the stakes are too high to not let the parent and patient know his/her strong opinion. He/she may believe that it is only right and appropriate that the child's care be transferred to the second center. A desire to use that patient in a research project may also play a role. PR#2 often does not communicate with PR#1 at all or by a letter weeks later.

But is this behavior best for the care of children with rheumatic diseases as a group or for the care of any one patient? It may be useful for one patient at any one time. But over time this consultation behavior is a "no win" situation for all. How is it bad? First of all, it may sour relationships between other compatible colleagues. No one particularly likes being disrespected. This in turn can encourage retaliatory behavior, gossip, and stress. Plus, if there was a problem in quality of care, PR#1 may not learn anything. As noted, PR#2 may not phone or send a letter to PR#1. If he/she does, the tone may alienate PR#1. PR#1 may not be open to suggestions or possible improvements in his/her usual practice guidelines. PR#1 and colleagues may never want to willingly refer a patient in the future to the other medical center for a second opinion and some brainstorming and cross-pollination. Why should they? They might just get criticized again. The possible benefit of synergy and symbiosis are lost.

There is other fallout. Our ability to do excellent research to some extent depends on our ability to work together. These competitive consultations make this cooperation and collaboration essential to clinical and basic research less likely. How do we work together in CARRA and PRINTO if we are not getting along well due to these consultation practices?

Granted it is not as simple as I've described it. Sometimes patients and families are going to move from center to center one way or another due to convenience, reputation, ambience, moving to a location closer to second center, personality, doctor-shopping, and who knows what. Insurance sometimes mandates switching centers. That is a given. Sometimes we disagree with the present treatment so much that it is hard to be positive about another center's and pediatric rheumatologist's care. But these consultations need not be critical, negative consultations and include overt efforts to recruit patients from one center to another.

Isn't this behavior just good marketing and center development? No, not really. Any patients you gain by these activities are likely to be outweighed by the friendly consultations and clinical and research collaborations one may receive if one practices a friendlier, collaborative, and educational consultation practice.

### **Recruiting patients with one disease for research purposes.**

Many of us have one disease that interests us the most and we may have research projects in diagnosis, treatment, or the basic or clinical science of those illnesses. We may have websites that promote our expertise in that area or other means of marketing. This is a slippery slope as there is a fine line between ethical marketing and creating an atmosphere that suggests that one center is the only center to care for a disease. Parents go online and call and may be encouraged to come for a second opinion.

Providing supportive consults for the original center is the better course and only taking on the patient if the original physician requests the transfer or the parents say that they are not going back to the original physician. If this consult is done, it should be done with the full intention of sending back the patient to the initial rheumatologist with useful suggestions and seeking cooperation with that rheumatologist in any research endeavor. It is important for the consulting rheumatologist to restrain herself or himself from actively courting the patient and the parents, subtly or overtly. It's not easy sometimes, but it's the right thing to do.

### **Elite medical centers and 'Meccas'**

Each of us would probably like our center to be a Mecca, a famous or well-known medical center, a center with a great reputation and many grants and gurus. Perhaps we would like to be the head honcho, the leader, the guru. But most centers are not among the top 5-10 centers in our region, country, or continent. We can still try to work with the national and regional referral centers in a collaborative fashion, recognizing their valuable role in providing state-of-the art consultations and research while keeping our role of providing local, accessible, competent, day-to-day team care.

I would argue against the practice of elite medical centers trying to attract many of the patients with a certain disease to their center, including teens. This effort can be for research purposes, for teaching and patient care, for financial marketing, and for reputation building. I think that we can phone the consultants (often internists), e-mail them, fax them, and ask for help when they can provide it. But I'd question the practice of referring all Takayasu teens to a referral center because they have an internist Takayasu clinic, no matter how many grants they have and how long their CV. Most are still internists and often treat teens as young adults, fully developed emotionally and physically. Is lupus the same disease in a 14 year old as it is in a 35 year old patient? I would think not. Similar, but definitely different. So ask their help but keep our patients as our team programs should be able to provide the best overall care.

Turning this around, we should attempt to work in a team-like fashion with adult rheumatologists who see kids with rheumatic disease at a distance from our center. We may not be as sympathetic with adult rheumatologists who see children right under our noses. But this

cooperation and collaborative effort is what's best for the children. It may be best for us to see the sickest kids in an adult rheumatologist's practice once every 6 months or once a year to add some new ideas.

This emphasis on the integrity and development of each rheumatology center regardless of size or resources may appear to conflict with the "centers of excellence" concept, but it doesn't have to. The major pediatric rheumatology centers can still be centers of excellence and remain collaborative, cooperative, and respectful of other centers as well as pursue their research and clinical goals.

### **A consultation protocol**

A protocol such as this may help:

- 1) In any one urban area, PR#2 immediately calls PR#1 in the area or region after PR#2 sees a patient of PR#1, whether the consultation is physician-initiated or parent-initiated.
- 2) The consultant rheumatologist and staff strive to present a neutral and professional consultation, devoid of any attempt to sell the patient and family on the merits of their program, hospital, and individuals.
- 3) In particular, the PR#2 should do his/her best to broadly support PR#1 and her/his program (even if it's different), while offering constructive suggestions to improve the care.
- 4) The consultant should endeavor to send the patient and family off with some new ideas with a pledge to call the original physician and discuss the case as well as provide a consultation letter to the physician and family. The family should be openly encouraged to return to the first rheumatologist even if the consulting physician thinks that he or she could do it better.
- 5) If the family is determined to switch care, the consulting physician should call and write the original doctor and discuss the consultation and the transfer of care.

**The idea is to keep things open and transparent, with an effort to educate each other rather than compete and dominate.** In 2005, there are plenty of patients for everyone and it may be best if we move from the attitude that we do it best to an attitude that let's all do it well together.

You may wonder who am I to talk? I could be better in this area. Yes, I've turned on the charm and hoped that a second opinion consultation patient may stay with me, especially if the child is cute. I've not communicated well with the other rheumatologist. Most of us have been possessive of new patients at any one time. But in my opinion it is not the best path for our young subspecialty and our patients. "That's naïve", people will say. Maybe it is. But we should be able to improve in this area. This is not about one person, one city, one region, one country. In my discussions with colleagues from all over the world, these problems are universal.

### **Conclusion**

We are in some ways a unique subspecialty. We're a small subspecialty and are likely to

remain so for awhile. We are mostly outpatient, often fly below the radar, but with fascinating, amazing, challenging illnesses to diagnose, treat, conquer and eliminate. We must bond together to help the 6 million children in the world with rheumatic diseases, working together internationally, nationally, regionally, **and** locally.

Short-term individual gains are only to mean long-term losses for our community. We can limit these practices while our brotherhood remains small. There is more than enough work for all of us.

Charles H. Spencer

Chicago