

*“A Letter to my Younger Colleagues” is a series of essays written by selected senior Canadian paediatricians, who were named as outstanding mentors by a prominent group of their younger peers. I hope you enjoy and treasure the rich pearls of wisdom that each author offers, based on a lifetime of professional practice and personal reflections.*

Andrew Lynk MD  
Assistant Editor, Paediatrics & Child Health

## Congratulations on passing your specialty examinations

Joe Clarke MD PhD FRCPC

Dear Allan,

Congratulations on passing your specialty examinations! Having known you as a resident, I was never in any doubt about the results. But it is good to know that it is all over ... or is it?

One of the best pieces of advice I ever received came to me just before I wrote my own specialty examinations 35 years previously. You may remember that I went from my paediatrics residency training at The Hospital for Sick Children (Toronto, Ontario) to McGill University (Montreal, Quebec) to pursue a PhD in biochemistry, with the ultimate objective of dedicating myself to a career in basic research. After more than three years in a laboratory, I decided, rather late in the day, to try the paediatrics specialty examinations. As they approached, I began to be bothered by the thought that I might just pass! After being in a laboratory for so long, without seeing patients, I didn't feel like a paediatrician. One morning, after a sleepless night worrying about all of this, I decided to call Harry Bain, who was a Professor of Paediatrics at The Hospital for Sick Children when I was a resident there, and easily one of the finest clinicians I have ever encountered. I related to him the nature of my dilemma, and his response stuck with me throughout my professional life. He said, “Passing the specialty exams does not make you a pediatrician – it makes it possible for you to become one”. In other words, Allan, he was saying that the learning process had just begun and would not, or should not, ever end, so long as you practice medicine.

The truth of what he said – and what I am passing on to you – became increasingly obvious with almost every patient I saw. Despite spending several hours each day in the laboratory, clinical practice in an academic setting became an important part of my work. I was amazed to discover that I seemed to learn something new from every patient I saw. The long-term importance of the commitment to life-long learning only became clear to me years

later, toward the end of my career, when I realized that easily 75% of the diseases I was managing on a daily basis were not even known to exist when I was a resident. I am in an unusual subspecialty, metabolic genetics, but conversations with senior colleagues convinced me that my experience was not unique. Think about it: in 1965, we knew almost nothing about the basic defect in lysosomal storage diseases; we hadn't even anticipated the peroxisomal disorders (such as Zellweger syndrome, X-linked adrenoleukodystrophy and Refsum's disease); awareness of the existence of the mitochondrial genome was still years away; mitochondrial cytopathies would have been considered material for a science fiction novel; and the fatty acid oxidation disorders, such as medium-chain acyl-coenzyme A dehydrogenase deficiency, which we now realize were relatively common causes of sudden unexpected death in infants, existed only in theory.

The take-home message, Allan, is that without a personal commitment to continuing self-education, you will inevitably and very quickly fall hopelessly behind. This is a disservice not only to your patients but also to yourself because you will be missing out on one of the most exciting aspects of the practice of paediatrics – it is a limitless source of awesome new discoveries.

Allan, the examinations are over. Well done. You have equipped yourself to become a paediatrician.

Dear Allan,

I hear that your practice is flourishing and that you have acquired a sizeable number of patients with chronic medical problems. By its nature, residency training tends to focus on acute medical problems, even in children who have underlying chronic conditions. As a result, one of the aspects of practice that ends up, more often than not, being learned ‘on the job’ is the management of children with chronic diseases.

---

*Division of Clinical and Metabolic Genetics, The Hospital for Sick Children, Toronto, Ontario; Service de génétique médicale, Centre hospitalier universitaire, Sherbrooke, Quebec*

*Correspondence and reprints: Dr Joe Clarke, Division of Clinical and Metabolic Genetics, The Hospital for Sick Children, 555 University Avenue, Toronto, Ontario M5G 1X8. Telephone 416-813-5340, e-mail joec Clarke@sympatico.ca*

*Accepted for publication September 26, 2009*

The learning is made infinitely easier when you take a team approach to it. You will no doubt say, “I know all that – I meet regularly with the physio [physiotherapist], the OT [occupational therapist] and the social worker in the management of my patients”. I am referring, however, to the most important members of the team – the child’s parents. Embracing a team approach to the care of chronic problems that includes the parents as true partners in management pays manifold dividends. First, it forces you to listen and to take what the parents say seriously. What they have to say is almost never found in textbooks or scientific articles. It deals with the day-to-day problems of the child and how the family overcame them. As you listen to more parents, you begin to see what works and what doesn’t work. You also learn that what works for some may not work for others. But this is to be expected because we are all different, including our patients. You will discover how inventive parents learn (through a certain amount of trial and error) novel and creative techniques for managing feeding problems, breathing difficulties, sleeplessness, challenges to mobility, and a million other apparently nonmedical problems that contribute to the overall well-being of their child.

Another dividend that derives directly from treating the parents like members of a management team is related ironically to the Internet. Increasingly, parents use the Internet to learn more about their child’s illness, whether it is a common condition or a very rare disease. You should encourage this, but be sure to tell them to contact you if they encounter advice that seems to be at odds with what you might have told them. If you discourage them from using the Internet, saying that the information is unreliable and “would only scare them”, they will use it anyway – they just won’t tell you because they have done something you told them not to do. They will, however, be left wondering what and who they should believe. By encouraging them and offering to discuss any apparent inconsistencies, you will have the opportunity to correct any misunderstandings they may have developed from something you may have said – which is more or less inevitable at least sometime in the management of most children – or they may actually discover something you didn’t know about. It takes a certain amount of courage to admit to the parents of your patient that they have discovered something you didn’t know before they told you about it. However, this will almost certainly happen sometime, and by accepting your role as one of the team, rather than the omniscient prescriber, you enhance the management of your patient – and you also stand to learn something new. Of course, this all takes time. But the time you spend with the parents of a child with a chronic medical condition is perhaps the most important therapeutic measure you have to offer.

Look forward to seeing you at the curling banquet.

Dear Allan,

I understand that you discovered that you had inadvertently offended the parents of one of your patients with a very rare medical condition, and you only found out about it by accident. You are wondering why the parents didn’t speak to you about their concerns, which had apparently evolved into real anger.

I think you have become an inadvertent victim of what I call the ‘hostage syndrome’.

When faced with an apparently hopeless sickness, patients and families often feel abandoned and intensely lonely. This is especially true if the illness is rare and the outcome of treatment is uncertain. The doctor is often seen by the patient’s parents as their only hope. The last thing they want is to have something happen that causes you, the doctor, to abandon their child, who they feel has already been abandoned by fate, by God and by the world. They often embark on what amounts to a curious form of negotiations, in which they may state their concerns or their needs obliquely to be sure not to risk offending you. This has the potential to create all kinds of miscommunication. I remember, for example, a parent who was invariably effusive in her praise of me, my skill as a physician, my bedside manner and even my clothing. I discovered from the nurse who works with me that something I had said, quite innocently, had left the parent with the impression that I would not be continuing to provide medical care for her child. She was ‘purchasing’ my commitment. Sometimes this actually takes the form of gifts. Gifts to doctors are often given out of genuine gratitude. However, sometimes, they are given in an attempt to buy the doctor’s care.

Be aware of the hostage syndrome. The signs are often subtle, but failure to recognize it may result in all kinds of avoidable trouble in the management of your patient with a rare, chronic illness.

Allan, you need a break. Why don’t you come out to our place in the country for a weekend and do some walleye fishing.

#### BIOGRAPHICAL NOTE: JOE CLARKE

Dr Joe Clarke is a Professor of Paediatrics at the University of Toronto (Toronto, Ontario) and former Director of the Genetic Metabolic Diseases Program at The Hospital for Sick Children (Toronto, Ontario). He is also a Clinical Professor in Paediatrics at the University of Sherbrooke (Sherbrooke, Quebec) and is currently a Senior Associate Scientist at the Research Institute of The Hospital for Sick Children.

His research relates specifically to the evaluation of innovative approaches to the treatment of lysosomal storage diseases.

Dr Clarke has authored or co-authored more than 180 peer-reviewed original articles in medical scientific journals, in addition to many book chapters.