Introductory Remarks

Welcome to the 2010 International Symposium on Dupuytren’s Disease. I am a hand surgeon and here’s my story. Larry Hurst and Marie Badalamente worked for years developing collagenase treatment for Dupuytren’s. Their industry partner hosted a Dupuytren’s patient on line discussion forum. A patient read about needle release on that forum and asked me to visit Paris and learn it. I did. Three things happened. First, I became very busy treating Dupuytren’s with this new procedure. I have now treated about 8000 Dupuytren hands. Second, I realized that I am very lucky, and wanted to give back to the community that gave me this opportunity, starting with this symposium. Third, I don’t have the answer for Dupuytren’s, and it’s driving me crazy. It’s a problem which faces all of us. We are not all that different. There’s a good chance that genetic testing would show that you and I share a common ancestor, and if we had better information on chromosome number 6, we might find that our common ancestor carried the gene for Dupuytren’s. Any of us could have Dupuytren’s.

The quest to find the best way to treat this has challenged the most talented people in the world for hundreds of years. In 1974, Marc Iselin posed a number of questions in a piece titled “Mysterious aspects of Dupuytren’s contracture”. If it’s not a tumor or infection, why does it act like one? Why is it so unpredictable? How does it form cords in areas where there really isn’t a defined fascia? Why does it blow up unpredictably after surgery? Forty years later, we only have more questions. Could it be a congenital viral infection? How can we turn it off? When is therapy not enough or too much? If it’s genetic, why is it so variable, both individually and in large groups of affected people? This list goes on forever, but really there is just one question: What do we have to ask, what do we have to know, what do we have to do to find a cure? Well, we start with meetings like this. This is the sixth, possibly seventh international meeting on Dupuytren’s. The first that I could find was organized in 1966 in Paris by Gossett, Tubiana and Hueston, then one in Turino, Italy in 1981. Professor Millesi chaired the 1983 Vienna meeting, McFarlane the 1985 London, Ontario congress. The 1991 Hannover symposium was led by Berger, Delbrück, Brenner and Hinzman. Nearly twenty 20 years later Hurst and Badalamente had a symposium in Stony Brook. Now, we meet in Miami.

These conferences have had three main topics: science, surgery and disease modification. In books on Dupuytren’s, if you count the pages, you’ll find that the great majority of writing has been split between science and surgery. But disease modification - that’s what we really need, because Dupuytren’s is not a surgical disease: it’s a medical condition for which there is not yet a medicine. We need to work together with this goal in mind. My hope is to spur efforts to make progress with disease modifying treatments. We’ll always need surgery, but we won’t always need much.

Dupuytren’s hands are all different, like snowflakes: one process, infinite variety. Most people who have surgery for Dupuytren’s do pretty well, but a significant number do very poorly. They don’t come back for another surgery. They say things such as “If I had known what I was getting in to, I never would have had that surgery”. You don’t hear that from people who have had surgery for other hand problems. Those of you who don’t offer alternative treatments for Dupuytren’s have no idea, really no idea at all, how many people there are who want to be treated but do not want and will not have surgery for Dupuytren’s.
The more you look at Dupuytren’s, from any angle, the more impossible it seems. It seems simple, but it’s not. How do you solve an impossible problem? Question convention. Examine failure. Engage outsiders. We are all outsiders. None of us truly understands Dupuytren’s, but we each have the gift of a unique perspective to contribute. We need to communicate. Blocked by different languages, different professional environments, and by the constraints of publishers, we are a Zen koan: If a tree falls in the woods, and someone sees it and writes a book about it, but doesn’t write clearly, and the book goes out of print, and time passes, did someone discover a falling tree? The answer? No. We can not work in isolation. We have to share what we know. Discover, simplify, communicate.

Dupuytren’s is genetic, it’s mechanical and it’s biological: it’s all of these; you can’t separate these and understand Dupuytren’s. The gap between the real thing and the laboratory model can be just as big a hurdle as the gap between the clinical plan and its execution. We have to cross these obstacles. And we can, because we have two strengths. Our first is that we are explorers – every one of us. We have a need to discover. We are comfortable with difficult challenges, each in our own way, and in our lives we each have witnessed things that few other people have seen. We all know that if we don’t reach for the unknown, we will never know what lies within our grasp. Our second strength is that we are all lifetime students. We are academics. We see the beauty of science in the universe, appreciate mathematics in everyday things, and enjoy learning new perspectives.

It’s a tough problem, but not impossible. There are three very interested groups who can and must work together: patients, researchers and clinicians. To this end, I established the Dupuytren Foundation, a charitable organization with a mission to promote efforts to find better treatment options for Dupuytren’s and related conditions. Dr. Wolfgang Wach created the Dupuytren Society, a patient oriented internet based association. The Foundation and the Society are the hosts of this symposium. The ultimate goal of this symposium is to create an academic international Dupuytren’s task force to develop and carry out large scale collaborative multicenter research and clinical studies to develop better treatment options for Dupuytren’s – to work for a cure.

Up to this point, international symposia on Dupuytren’s have been about current concepts, state of the art. This symposium is about the future. Inroads into Dupuytren’s disease modification has potential impact on the treatment of other fibrotic conditions including pulmonary fibrosis, renal interstitial fibrosis, cirrhosis, scleroderma and other life altering conditions. We all stand on a great threshold. Welcome to the 2010 International Symposium on Dupuytren’s Disease. Here is your chance to make a difference.

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