



THE TRANSVERSE MYELITIS ASSOCIATION

Advocating for those with rare neuroimmunologic disorders

WELCOMING REMARKS THURSDAY, JULY 12, 2001

- SANDY SIEGEL

Deanne, Debbie, Paula, Maureen, Rich, Drema, Heather, Phil, Pauline and myself met for the first time in May of 1998. We were guests of Dr. Charles Levy, the National Organization of Rare Disorders and the International Fybrodysplasia Ossificans Progressiva Association. It was an enlightening weekend in Columbus, Ohio. Spending a few days with a group of people with FOP offers a lifetime of perspective on the blessings we have when our bodies are in working order. Beyond the experience of learning from a group of very courageous people with FOP, there was this small group of us associated with TM who saw first hand the social and emotional power that evolves from the opportunity to share in the personal experiences which surround having a rare disease. FOP is a disease that affects just hundreds of people, and they have merely a few doctors who have developed an interest in performing research on the causes and treatments for this truly amazing condition. We readily observed that their gathering was a catharsis for their souls, it was an awakening of spirit and it was a celebration of hope.

It was during that weekend that the officers of The Transverse Myelitis Association vowed to each other that we would bring together people with TM and offer them this important opportunity; to share in experience, to help people with TM feel less isolated, to encourage education and research on this

condition, and to offer people great hope for their futures. It was through that promise that we came together in Seattle in 1999 for the First International Transverse Myelitis Association Symposium.

Today, it is my great pleasure to welcome you to the Second International Transverse Myelitis Symposium. We greatly appreciate the attendance and participation of the medical community and are grateful for your taking time from your busy schedules to share information with us about your exciting progress in transverse myelitis research, as well as sharing treatment information with those of us who have TM and our caregivers. Most importantly, we are grateful for your interest in Transverse Myelitis. It is through this interest, and your concern for the well being of the people who have this condition that we derive our greatest hopes for the future.

I would like to thank Debbie Capen and Paula Lazzeri for all of the work they perform as officers and board members of the TMA. They make time in their busy lives filled with family and work to devote hundreds of hours to keep the TMA running. And both of them perform these duties in spite of the many physical challenges they face with TM. We love you, both, and are so grateful for all of what you do for all of us.

We would also like to thank all of the members of The Transverse Myelitis Association who have come here from all over the country and from all over the world. We understand the great sacrifices you have made to be here; and we are grateful for your being able to share in this wonderful and important experience.

For many of you, this will be your first opportunity to meet others with the TM diagnosis. Over this weekend, many of you will begin special relationships with each other that will last a lifetime and will provide you with comfort and support through difficult times. For who else will know what you are going through better than they.

For all of us, we heard the words 'transverse myelitis' for the first time when we were diagnosed with this condition, or when our loved ones were given this diagnosis. None of us had ever known anyone who had this condition; we did not have any experience or context through which to consider a prognosis. And the information we received from our physicians was confusing and ambiguous. The result for all of us was that we felt so isolated, we were frightened and we were so confused. There was no one to turn to and there was no information to help us understand what was happening to our bodies or to help us understand what our futures might hold.

Well, we are here this weekend and you can look around the room -- you are not alone. And we are here with a room full of physicians and scientists who are trying to better understand transverse myelitis. They are interested in what is happening to us and our loved ones. We are all very excited about the possibilities that your research holds for us - and it does provide us with great hope.

I would like to thank the TMA Medical Advisory Board for being here and for participating in the symposium: Dr. James Bowen from the University of Washington, Dr. Douglas Kerr from The Johns Hopkins University School of Medicine, Dr. Charles Levy from the University of Florida, and Dr. Joanne Lynn from The Ohio State University. The TMA would like to offer our deepest gratitude to Dr. Charles Levy for initiating our Medical Advisory Board. He came forward to offer his help without solicitation and at a time in the Association's development when we needed expert guidance and support. He is a wonderful doctor and a very special person. The physicians on our board offer us advice and counsel, they help us educate our membership, and most importantly, they help us by providing excellent treatment and care for people who have TM. We are excited about the expanding role of our medical advisory board as we look toward raising significant dollars to fund TM research in the future.

We would also like to thank Cody and Shelley Unser from the Firststep Foundation for helping to sponsor this symposium and for their great efforts in motivating the development of the TM consortium. Cody has selflessly and generously worked to bring awareness to TM and to help educate the public about this condition. We are very proud and grateful for her work on behalf of all of us whose lives are impacted by TM.

I would like to recognize two very special people who are not in Baltimore with us this weekend, Deanne Gilmur and Jim Lubin. Both Deanne and Jim are board members of the TMA. In 1994 Deanne very courageously founded the TMA. She and her husband, Dick, experienced the isolation, fear, and uncertainty when their 18-month-old daughter contracted TM. It takes a very special person to go through these challenges and maintain a positive attitude about life. It takes an even more special person who can reach beyond their own challenges to want to help others. That is Deanne. We are glad that Dick is here with us representing the Gilmur's, but Deanne will be missed. We love you, Deanne, and will look forward to seeing you next summer in Columbus for the TMA Children's Workshop.

I found Jim Lubin on the Internet; it is the perfect place to meet Jim. Pauline and I typed the words 'transverse myelitis' into the Yahoo search engine, and Jim's disability resources page appeared on our screen. We began corresponding with Jim; he was the first person we had ever met who had TM. He had recently started the transverse myelitis internet club, a list group for people with TM. The synergies between a support and advocacy group and the Internet were obvious. We enlisted Jim's help and he became an officer and board member of the TMA. Jim is our Information Technology Director. Today, we have more than 350 people from all over the world who participate in our internet club. The exchange of information and support goes on 24 hours a day, 7 days a week, and every single day of the year.

We are very proud of our web site. We know how important that site is for people who are recently diagnosed with TM and for people who have had TM for years. The positive response we receive from people and from organizations about our site is truly gratifying. In 1997, the TMA had 187 members. Today, we have 3200 members from every state in the United States and from more than 40 different

countries; and we have support groups in Australia, England, Ireland and South Africa. Jim's creativity, technical skill and compassion account for much of our outreach and advocacy success.

We are so proud of the wonderful and important work that Jim does for all of us. He is such a remarkable person. Jim contracted TM in 1991; he is a full quadriplegic and is ventilator dependent. He performs all of his computer work by sipping and puffing Morse code into an adaptive device. Jim has created a way for his mind and heart to reach well beyond the tremendous physical limits that have devastated his body. There isn't a day that goes by that I don't think about Jim and his dependence on the ventilator for his very life. I am here this weekend to listen to the research and the progress you are making in understanding TM. We need to get Jim off of his ventilator - that is how I will measure the success of the research. And it is with all of my heart and with all of my prayers that you are able to accomplish this progress soon.

Finally, I would like to thank Dr. Douglas Kerr and The Johns Hopkins University Medical School for hosting the transverse myelitis symposium. Dr. Kerr has worked tirelessly to organize a wonderful symposium and has brought together such a distinguished group of physicians and scientists as presenters. We know that it is going to be a very exciting and informative weekend.

Words just cannot adequately convey our sense of gratitude for all of what Dr. Kerr has accomplished in the past two years for treatment, research, education and awareness of TM. By starting the Johns Hopkins Transverse Myelopathy Center, Dr. Kerr provided a focused approach to TM treatment and research. The center has seen more than 200 TM patients. In addition to the strides made in treatment and research, the center also brings hope to people with TM for they can now see that there is an organized and concerted effort to deal with their problems. Dr. Kerr is a skilled and compassionate doctor, but most of all, Doug is a mensch. We are so proud of our association with you, and so blessed to have your interest and your support. It is my great honor to introduce to you, Dr. Douglas Kerr.