



2013 ERDHEIM-CHESTER DISEASE



PATIENT AND FAMILY GATHERING

HOSTED BY THE ECD GLOBAL ALLIANCE





ECD Global Alliance

Supporting Those Affected by Erdheim-Chester Disease

www.erdheim-chester.org

P.O. Box 775, DeRidder, LA 70634

337-515-6987

November 1, 2013

Welcome to San Diego and the first ever International ECD Patient and Family Gathering!

Your involvement and attendance is very much appreciated. It is our hope that this meeting will mark the beginning of an annual event for fellowship among the ECD community and the presentation of new scientific findings and research related to Erdheim-Chester Disease.

We hope you will find this meeting helpful to you and your circumstances. There will be opportunities to hear from leading ECD researchers, to learn from experts about healthy life style choices, to interact with other ECD patients and family members, and to help set the direction for the ECD Global Alliance.

The ECD Community is extremely grateful for your involvement in the organization and sharing of your experiences. Please let us know how the organization can best serve you and if you are interested in getting more involved in the work of the organization. We are certain your contributions would be valuable!

Enjoy your visit to sunny San Diego!

*The ECD Global Alliance
Board of Directors
- Kathy*

ECD Global Alliance - A non-profit 501(c)(3) org

Board of Directors: Linda Adams, PhD, Kathy Brewer (President), Pam Fleming, Rachel Mitchell (Treasurer), Glenn Padnick
Juvanee Estrada-Veras, MD (NIH Federal Liaison for the ECD Global Alliance)

**Erdheim-Chester Disease
Patient and Family Gathering
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B. October 31 and November 1 Patient and Family Gathering Agenda

October 31, 2013

Pre-Registration for the ECD Patient and Family Gathering 1st Floor – North Tower

Time	Activity	Location
5:00 – 7:00 pm	Patient and Family Gathering Early Registration	San Diego Foyer outside San Diego Ballroom B

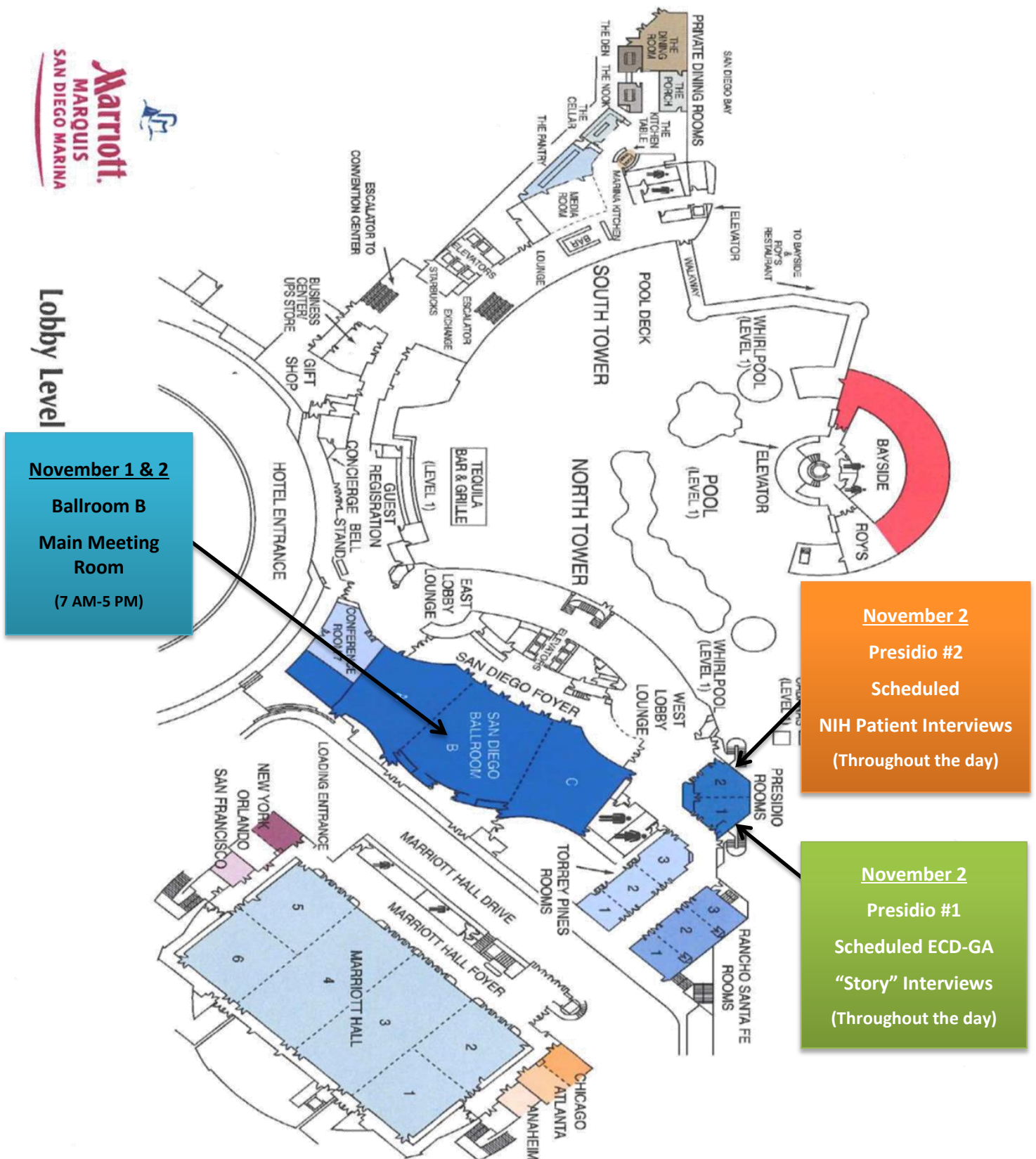
November 1, 2013

ECD Patient and Family Gathering Agenda Hearing from the “Experts” 1st Floor – North Tower

Time	San Diego Ballroom B	Presidio Room	Torrey Pines Room #2	Torrey Pines Room #1
7:00 – 8:00 am	Registration and Breakfast; ECD Video Viewing at 7:30 am	Open Fellowship and Rest Area		
8:00 - 8:20 am	Welcome / Meeting Logistics	Open Fellowship and Rest Area		
8:20 – 8:50 am	Role of diet and exercise in neurologic disease ✓ <u>Dr. Timothy Vollmer</u> , ¹ Neurology, University of Colorado; Aurora, CO, USA	Open Fellowship and Rest Area		
8:50 – 9:30 am	ECD Treatment Options Panel Discussion. ✓ <u>Dr. Lorenzo Dagna</u> , ² (Panel Moderator), Internal Medicine, San Raffaele Scientific Institute; Milan, ITALY ✓ <u>Dr. Achille Aouba</u> , Hematology, Hôpital Necker-Enfants Malades; Paris FRANCE ✓ <u>Dr. Mark Heaney</u> , Oncology, Columbia University Medical Center; New York, NY, USA ✓ <u>Dr. David Hyman</u> , Oncology, Memorial Sloan-Kettering Cancer Center; New York, NY, USA	Open Fellowship and Rest Area		
9:30 – 9:45 am	Break			
9:45 – 10:45 am	ECD Studies/ Research Panel Discussion: ✓ <u>Dr. Estrada-Veras</u> , ³ (Panel Moderator) Genetics, NIH; Bethesda, MD, USA ✓ <u>Dr. Omar Abdel-Wahab</u> , Hematology/ Oncology, Memorial Sloan-Kettering; New York, NY USA ✓ <u>Dr. Lorenzo Dagna</u> , Internal Medicine, San Raffaele Scientific Institute; Milan, ITALY ✓ <u>Dr. Augusto Vaglio</u> , ⁴ Nephrology, Parma University; Parma, ITALY	Open Fellowship and Rest Area		

Time	San Diego Ballroom B	Presidio Room	Torrey Pines Room #2	Torrey Pines Room #1
10:45 – 11:00 am	Break			
11:00 – 11:30 am	Round table discussion with all Medical Professionals in attendance. Q&A format ✓ <u>Dr. Omar Abdel-Wahab</u> , ⁵ (Panel Moderator), Hematology/ Oncology, Memorial Sloan-Kettering; New York, NY USA	Open Fellowship and Rest Area		
11:30 – 1:00 pm	Lunch – Served in San Diego Ballroom C			
1:00 – 1:30 pm	Alternative Medicine as Adjuncts to Traditional Medicine ✓ <u>Dr. Caroline Bjonback</u> , ⁶ Primary Care Physician, Bjonback Holistic Medicine and Acupuncture; La Porte, IN, USA	Open Fellowship and Rest Area	Managing the Emotional and Stressful Aspects of Caregiving (Caregivers Only) ✓ <u>Alejandra Ceja-Aguilar, MA</u> , ⁷	
1:30 – 2:00 pm	Physical Therapy and ECD ✓ <u>Dr. Ana Acevedo</u> , ⁸ Physiatrist , NIH; Bethesda, MD, USA	Open Fellowship and Rest Area	Southern Caregiver Resource Center in San Diego, CA, USA	
2:00 – 3:00 pm	Mindfulness Techniques ✓ <u>Allan Goldstein</u> ⁹ & <u>Cassondra Graff, MS, LCSW</u> ¹⁰ , UCSD Center for Mindfulness; San Diego, CA, USA	Open Fellowship and Rest Area		Scheduled NIH Patient Interviews
3:00 – 3:15 pm	Break			
3:15 – 3:45	Communicating With Medical Professionals & Keeping Medical Records ✓ <u>Cindy Livings, RN</u> ¹¹ , Spouse of ECD Patient; IN, USA			
3:45 – 4:00 pm	Organizational Overview and Direction Setting ✓ <u>ECD Global Alliance</u>	Open Fellowship and Rest Area		Scheduled NIH Patient Interviews
4:00 – 4:30 pm	Enjoying San Diego ✓ <u>Ted File</u> , ¹² San Diego Tourism; San Diego, CA, USA	Open Fellowship and Rest Area		Scheduled NIH Patient Interviews
4:30 – 4:45 pm	Photo Opportunity			

C. Map of November 2 Meeting/Activity Locations – North Tower



D. November 2 Patient and Family Gathering Agenda

November 2, 2013

**ECD Patient and Family Gathering Agenda
Patient Round Table Discussions or Your Day at Leisure in San Diego
1st Floor – North Tower**

Time	San Diego Ballroom B	Presidio #1	Presidio #2
7:00 – 8:30 am	Registration and Breakfast		
8:30 – 8:40 am	Welcome & Agenda Overview ✓ <u>ECD Global Alliance</u>		
8:40 – 9:00 am	ECD – A Personal Account ✓ <u>Gadi Bauchman</u> , ¹³ husband of an ECD patient	Scheduled ECD-GA “Story” Interviews	Scheduled NIH Patient Interviews
9:00 – 10:00 am	Patient Round Table Discussion ✓ Treatments, Side Effects and Coping Mechanisms – Your Experiences	Scheduled ECD-GA “Story” Interviews	Scheduled NIH Patient Interviews
10:00 – 10:15 am	Break	Scheduled ECD-GA “Story” Interviews	Scheduled NIH Patient Interviews
10:15 – 11:15 am	Patient Round Table Discussion ✓ Caregiver Coping Techniques – What do you do?	Scheduled ECD-GA “Story” Interviews	Scheduled NIH Patient Interviews
11:15 – 1:00 pm	Lunch on Your Own		
1:00 – 2:00 pm	Patient Round Table Discussion ✓ Exercise and Physical Therapy & Independent Living Experiences	Scheduled ECD-GA “Story” Interviews	Scheduled NIH Patient Interviews
2:00 – 3:00 pm	5 Pillars of a Healthy Diet ✓ <u>Dr. Gordon Saxe</u> , ¹⁴ Preventive Medicine, Center for Integrative Medicine, UCSD, San Diego, CA, USA		
3:00 – 3:15 pm	Break	Scheduled ECD-GA “Story” Interviews	Scheduled NIH Patient Interviews
3:15 – 4:30 pm	Patient Round Table Discussion ✓ <u>Christina Baker</u> , What more can ECD – GA Do?		
4:30 – 5:00 pm	Hugs & “Hope to See You Soon”		

E. Presenter Biographies

1. Timothy Vollmer, MD

Neurology, University of Colorado School of Medicine; Aurora, Colorado, USA

Timothy L. Vollmer, MD, is a Tenured Professor of Neurology and Neurosciences at the University of Colorado School of Medicine in Aurora, Colorado. He is Director of Neuroscience Clinical Research at CU, Medical Director of the Rocky Mountain Multiple Sclerosis Center, and Co-Director of the Rocky Mountain MS Clinic at the Anschutz Medical Campus.

Dr. Vollmer received a bachelor's degree with highest honors from the University of Wyoming and an MD from Stanford University. He completed his residency in neurology and post-doctoral fellowship in neuro-immunology at Stanford University. He joined the faculty of Yale University in 1987 where he was Director of the Multiple Sclerosis Research Center at Yale until 2002. He was the VanDenburgh Professor and Chair of the Division of Neurology at Barrow Neurological Institute at St. Joseph's Hospital and Medical Center in Phoenix, AZ from 2002 to 2008.

Dr. Vollmer has an international reputation in neurology related to his clinical expertise and research efforts concerning inflammatory diseases of the nervous system, most notably multiple sclerosis. He lectures and teaches widely in the United States and Europe. He is an expert in MS and other immune mediated diseases of the nervous system, and has participated in over 100 clinical research studies on new therapies for MS and has published over 150 peer reviewed papers and book chapters.

The RMMSC Clinic has over 8000 MS patient visits per year. Dr. Vollmer's current research activities include investigations into the mechanism of neuronal death in MS and a vaccine approach to immunomodulatory therapy in MS. He is currently the principal or co-investigator in 41 clinical studies at the University of Colorado Denver. With a specialty in neuroimmunology, ECD patient care and treatment can sometimes fall into his area of responsibility. Dr. Vollmer sits on the ECD Global Alliance Medical Advisory Board.

2. Lorenzo Dagna, MD

Internal Medicine, Vita-Salute San Raffaele University School of Medicine; Milano, ITALY

Lorenzo Dagna graduated in Medicine in 1999 and is Board Certified in Internal Medicine. He is currently an Associate Professor of Medicine and Vice-Coordinator of the San Raffaele International MD Program at Vita-Salute San Raffaele University, in Milano, Italy. Prof. Dagna is also Coordinator of the Clinical Immunology and Immunopathology Unit at the Department of Internal Medicine, and Director of the Rare Immune-mediated Disease Unit, both at San Raffaele Scientific Institute, Milano.

The clinical activity of Prof. Dagna is primarily focused on the care of patients with immunological and rheumatic diseases, in particular those with rare immune-mediated disorders. He is also involved in both basic and clinical research on the immunopathogenesis and immunotherapy of those diseases, with a particular interest on the mechanisms of histiocyte recruitment and activation in Erdheim-Chester disease.

Lorenzo Dagna is a Fellow of the American College of Physician (ACP), Honorary Fellow of the European Federation of Internal Medicine (EFIM), and member of the Italian Society for Internal Medicine (SIMI). He serves as the Section Editor for Immunology and Rheumatology for the European Journal of Internal Medicine.

Prof. Dagna is Chair of the Rare Disease Working Group of the European Federation of Internal Medicine, member of the International Foundation of Medicine Oversight Committee of the National Board of Medical Examiners (NBME, Philadelphia, PA), member of the Healthcare Professionals Working Party of the European Medicine Agency (EMA, London, UK), and member of the Medical Advisory Board of the Erdheim-Chester Global Alliance (DeRidder, LA). Dr. Dagna and his research team were the recipients of the 2010 ECD Global Alliance Research Grant.

3. Juvianee Estrada-Veras, MD

Genetics, National Human Genome Research Institute, National Institutes of Health; Bethesda, Maryland, USA

Juvianee Estrada-Veras, MD, is a Clinical Investigator and Staff Clinician at National Human Genome Research Institute (NHGRI) at the National Institutes of Health (NIH) in Bethesda, Maryland, USA.

Dr. Estrada-Veras received his MD magna cum laude from the Instituto Tecnológico de Santo Domingo (INTEC), Dominican Republic in 2003. He completed his residency at the State University of New York Health Science Center at Brooklyn and Downstate Medical Center with the Department of Pediatrics in 2009, and a fellowship at the National Institutes of Health/National Human Genome Research Institute, Bethesda, Maryland in Clinical Genetics and Medical Biochemical Genetics in 2011.

He is the Principal Investigator of the Erdheim Chester Disease Natural History Protocol at the NIH, and an Associate Investigator with Dr. William Gahl and colleagues in the study for diagnosis and treatment of inborn errors of metabolism at the NHGRI.

Dr. Estrada -Veras is a member of the ECD Global Alliance Board of Directors as the US Federal Liaison for the ECD Global Alliance.

4. Augusto Vaglio, MD, PhD

Nephrology, Parma University; Parma, ITALY

Augusto Vaglio, MD, PhD, is a Nephrology Consultant with the Dept. of Clinical Medicine and Nephrology at the University Hospital of Parma, Italy.

Dr. Vaglio received his MD magna cum laude from the School of Medicine at Parma University, Italy in 2000. His fellowship in nephrology was completed in 2005 at the University of Parma, magna cum laude.

Dr. Vaglio's clinical activity has focused mainly on the clinical management of patients with immune-mediated diseases, particularly retroperitoneal fibrosis and systemic vasculitis, and renal transplant patients. His main fields of interest are: retroperitoneal fibrosis and related diseases, systemic small vessel vasculitis, immunotherapy for renal cell cancer and pathogenesis of autoimmune diseases. He is the coordinator of a pilot trial of prednisone and sirolimus in patients with Erdheim-Chester Disease and is actively involved in clinical and pathogenetic studies on this topic. He is also the proponent of a large multicentre survey aimed to explore the presence of different clinical subsets of Erdheim Chester.

Dr Vaglio has authored 76 articles published in international peer-reviewed journals, with a cumulative Impact Factor of 550 and an h-index of 20.

Dr. Vaglio is a member of the ECD Global Alliance Medical Advisory Board.

5. Omar Abdel-Wahab, MD

Hematology/Oncology, Memorial Sloan-Kettering Cancer Center; New York, New York, USA

Omar Abdel-Wahab, MD, is an Assistant Member with the Human Oncology and Pathogenesis Program at Memorial Sloan-Kettering Cancer Center in New York, New York, USA.

Dr. Abdel-Wahab received his MD from Duke University School of Medicine in Durham, North Carolina in 2004 where he was a member of Alpha Omega Alpha. He completed Residency in Internal Medicine at Massachusetts General Hospital, Boston, MA in 2007. In 2009 completed a fellowship in hematology/oncology at Memorial Sloan Kettering Cancer Center, New York, NY.

Dr. Abdel-Wahab specializes in the research and treatment of patients with a variety of myeloid malignancies. These include myeloproliferative neoplasms, myelodysplastic syndromes, and acute myeloid leukemia.

He currently spends the majority of his time in laboratory-based research investigating the underlying causes of these disorders through genomic studies of patient samples as well as in vitro and in vivo models. As a member of the laboratory of Ross Levine in the Human Oncology and Pathogenesis Program, he has helped to identify and characterize several new genetic abnormalities in the diseases mentioned above. In addition to increasing our understanding of the causes of these disorders, these discoveries have promise in helping to discover novel targeted therapies.

Dr. Abdel-Wahab and his associates were the recipients of the 2013 ECD Global Alliance Research Grant.

6. Caroline Bjonback, MD

Primary Care Physician; Bjonback Holistic Medicine and Acupuncture; La Porte, Indiana, USA

Caroline Bjonback, MD, is board certified in Family Practice and practices Family Medicine and Acupuncture in La Porte, Indiana. She obtained her medical degree from the University of Colorado Health Sciences Center in 1985. She then did an internship at the Pasqua Hospital in Regina, Saskatchewan, Canada. She worked in the emergency room for one year and then did family practice in Regina for several years mainly doing women's health and obstetrics. In 1995 she became board certified in Family Practice in Canada. Later in 1995 she was recruited to work in family practice in La Porte, Indiana and moved back to the states. She was board certified in family practice in the US in 1997.

Caroline became interested in alternative medicine while in medical school in Colorado and took a course in holistic medicine. Since that time she has studied many aspects of alternative medicine on her own. In 1999 she met Billie Topa Tate, an Apache shaman and healer. Over the last 14 years she has studied Reiki and various healing modalities with Billie. Caroline is currently a Reiki Master Teacher 6th degree.

In 2003 Caroline studied medical acupuncture through UCLA and the Helms Institute. She has taken further courses in Traditional Chinese Medicine and herbal medicine, as well as various continuing medical education courses through the American Academy of Medical Acupuncture.

She currently practices family medicine half time and holistic medicine/acupuncture half time dividing her time between the two practices.

7. Alejandra Ceja-Aguilar, MA

Southern Caregiver Resource Center; Director of Education and Outreach; San Diego, California, USA

Alejandra was born in México and was raised in Idaho. She has a Bachelor's degree from the University of Utah and another in Spanish from the Autonomous University in Barcelona. While living in Spain, Alejandra took advantage of her time in Europe exploring Italy, France, and other areas of Spain. To this day, her favorite spot continues to be Florence, Italy.

In 2007, she obtained a Master's Degree in Counseling from the University of San Diego. While at USD, Alejandra participated in a study abroad program in Bangkok, Thailand and was able to continue developing her passion for the diverse family structures that exist all over the world. Upon graduating, Alejandra was hired as a counselor and educator at a charter school in San Diego, supporting English Language Learners and teaching Action Research. In addition, Alejandra was invited to join the faculty at the Autonomous University of Baja California's Department of Psychology, teaching Action Research.

In 2009, Alejandra joined the team at Southern Caregiver Resource Center (SCRC), one of the eleven Caregiver Resource Centers of California, providing free comprehensive support services to families and friends providing care to an adult with a chronic or disabling condition. As Director of Education and Outreach, Alejandra provides educational presentations and trainings, in English and Spanish, to family caregivers and service providers throughout San Diego County and Imperial County, focusing on the importance of self-care while caring for others. And as fate would have it, shortly after Alejandra joined SCRC, her maternal grandmother was diagnosed with Alzheimer's disease. This has given Alejandra a personal connection to the many family caregivers she meets on a daily basis.

8. Ana T. Acevedo, MD
Physiatrist, National Institutes of Health; Bethesda, Maryland, USA

Ana T. Acevedo, MD, a senior staff physiatrist in Rehabilitation Medicine at the NIH Clinical Center, is a Diplomate of the American Board of Physical Medicine and Rehabilitation. She is a graduate of the UCCEM medical school. She completed her internship in internal medicine at Saint Agnes Hospital in Baltimore and her residency training in Physical medicine and rehabilitation at the Sinai Hospital-Johns Hopkins University program. Subsequently, she completed a fellowship in Pediatric Rehabilitation at Children's Hospital National Medical Center in Washington, D.C.

Dr. Acevedo has over 27 years of experience in the field of physical medicine and rehabilitation. She has been an active member of the American Academy of Physical Medicine & Rehabilitation since 1984. Her special interests include the diagnoses and treatment of acute and chronic musculoskeletal pain; and assessing adults and children with disabilities to help them improve their quality of life. She has lectured extensively in multiple rehabilitation medicine related topics. Dr. Acevedo is fluent in English and Spanish. She joined the Rehabilitation Medicine department at the NIH Clinical Center in January of 2010. She currently collaborates with the NHGRI in evaluating patients with rare and undiagnosed diseases.

9. Allan Goldstein, Senior Teacher
Managing Director, UC San Diego Center for Mindfulness; San Diego, California, USA

Allan Goldstein has been involved in learning and teaching Mindfulness-Based Stress Reduction Programs (MBSR) since participating in his first program in 1993. Since that time he has trained in facilitating MBSR with the University of Massachusetts Center for Mindfulness (CFM) and has gone on to teach MBSR to groups and individuals in universities, business and community settings. His work has also led him to teaching in military installations and even in the virtual world of Second Life. Allan has a strong passion for promoting the valuable work of mindfulness-based interventions and applies that passion in his role as Managing Director, spearheading marketing and program development efforts of the center, as well as leading MBSR and other mindfulness groups.

10. Cassondra Graff, MS, LCSW
MBSR Teacher
Speakers Bureau Coordinator, UC San Diego Center for Mindfulness; San Diego, California, USA

Cassondra Graff, LCSW, is a licensed psychotherapist with a private practice in Rancho Bernardo, California. She has trained in MBSR through the University of Massachusetts Medical Center program, under the direction of Jon Kabat-Zinn and Saki Santorelli. Cassondra completed a training in Mindful Self-Compassion (MSC) under the direction of Kristin Neff and Christopher Germer. She has also trained in MBSR and MSC at UCSD Center For Mindfulness. Cassondra is a graduate of Columbia University in New York. Cassondra's personal mindfulness practice inspires her work as a teacher and psychotherapist. She believes in the power and potential of mindful awareness to help us navigate life with greater wisdom, health and sense of well-being.

11. Cindy Livings, RN

Spouse of ECD Patient; Florida, USA

A Registered Nurse, Cindy Livings earned her Bachelor of Science in Nursing from the University of Southern Mississippi in 1981. She worked in the areas of oncology, neurosurgery and gastroenterology. After 7 years of nursing experience, she switched gears to become a public school educator. In 1989 she began her teaching career and for 3 ½ years she taught middle school math and science. In 1992 she initiated the Medical Science program at Vero Beach High School. Since that time, she has taught over 3000 young adults who have gone on to become medical doctors, nurse practitioners, physician's assistants, dental hygienists, pharmacists, etc. In 2000 she was named a National Board Certified Teacher in the field of Career & Technical Education.

Married since 1981 to her high school sweetheart, Cindy is also the primary caregiver for her husband Mike who was diagnosed with ECD in 2009. Together, Cindy and Mike are the parents of 3 grown children and 1 spoiled rat terrier, and have 3 grand-dogs and 1 grand-horse.

Cindy's knowledge & expertise are an original amalgamation of experiences – from her nursing background to the 'school of hard knocks' as Mike's ECD was diagnosed, then progressed.

Originally from Alabama, they have lived in Vero Beach, Florida, since 1983.

12. Ted File

Director of Site Experience & Conference Services San Diego Tourism Authority; San Diego, California, USA

Ted File believes himself to be a Local, although he was not born in San Diego. Having lived in "America's Finest City" for 11 years he does refer to himself as a Native. For the past 5 years Ted has been working for the San Diego Tourism Authority and is responsible for showcasing San Diego to potential clients who are considering San Diego for a future meeting.

13. Gadi Bauchman,

Spouse of ECD Patient; Israel

Gadi Bauchman lives in Israel and is married with 3 children. Gadi graduated with a BA in business management and a BA in electrical engineering. He has worked in the high-tech market for 20 years with vast experience in project management, research and development, customer support, and operations management. Gadi has experience as a startup entrepreneur. He served as Captain in the special units at the IDF (Israel Defense Forces). Gadi currently holds the position of VP of Operations in a high-tech company.

14. Gordon Saxe, MD, PhD, MPH

Preventive Medicine, Center for Integrative Medicine, University of California San Diego; San Diego, California, USA

Dr. Gordon Saxe is a preventive and integrative medicine physician, a founding member and Director of Research of the UC San Diego Center for Integrative Medicine, and the Medical Director of the UC San Diego Natural Healing & Cooking Program.

Dr. Saxe received his MD at Michigan State University, his PhD in Epidemiology at the University of Michigan, and his MPH in Nutrition at Tulane University. He completed residency training at the University of Massachusetts and is board certified in Preventive Medicine.

His research has been supported by grants from the National Institutes of Health, the American Cancer Society, and The Cancer Project. He is also a national expert in the fields of diet and cancer, integrative oncology, and the use of food as medicine and is most well-known for his pioneering work in the combined use of a plant-based diet and body-mind stress reduction to control the progression of advanced prostate cancer. His previous research has focused on the epidemiology of diet and cancers of the prostate, breast, and pancreas; the role of diet, body-mind exercise, and other natural therapies to control the spread of cancer; and the effects of diet and lifestyle factors on gene expression in prostate cancer.

“The ECD Patient and Family Gathering is supported, in part, by funding from Genentech.”



“Supporting those affected by Erdheim-Chester Disease”