



ERDHEIM-CHESTER DISEASE
2ND ANNUAL INTERNATIONAL
PATIENT AND FAMILY GATHERING
PROGRAM
SEPTEMBER 18 - 20, 2014



“Hope Beyond Borders”



ECD Global Alliance

Supporting Those Affected by Erdheim–Chester Disease

www.erdheim-chester.org P.O. Box 775, DeRidder, LA 70634 337-515-6987

September 18, 2014

Welcome to Bethesda and the 2nd Annual International ECD Family and Patient Gathering!

Thank you for your attendance and involvement in this year's event. "Hope Beyond Borders" is our theme for this year highlighting the global nature of our community. We are optimistic that you will enjoy the ECD community fellowship and find the diverse presentations helpful.

We are hopeful that the gathering is enlightening and encouraging to you and your family. There will be opportunities to hear from experts about treatment and research information, to learn more about the Social Security process, to interact with other ECD patients and family members, and to find ways to help the ECD organization grow.

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. Your contributions have proven to be invaluable!

Please enjoy your visit!

The ECD Global Alliance Board of Directors and Staff

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)

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2nd Annual International Patient and Family Gathering

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A. September 18 & 19 Meeting Agenda

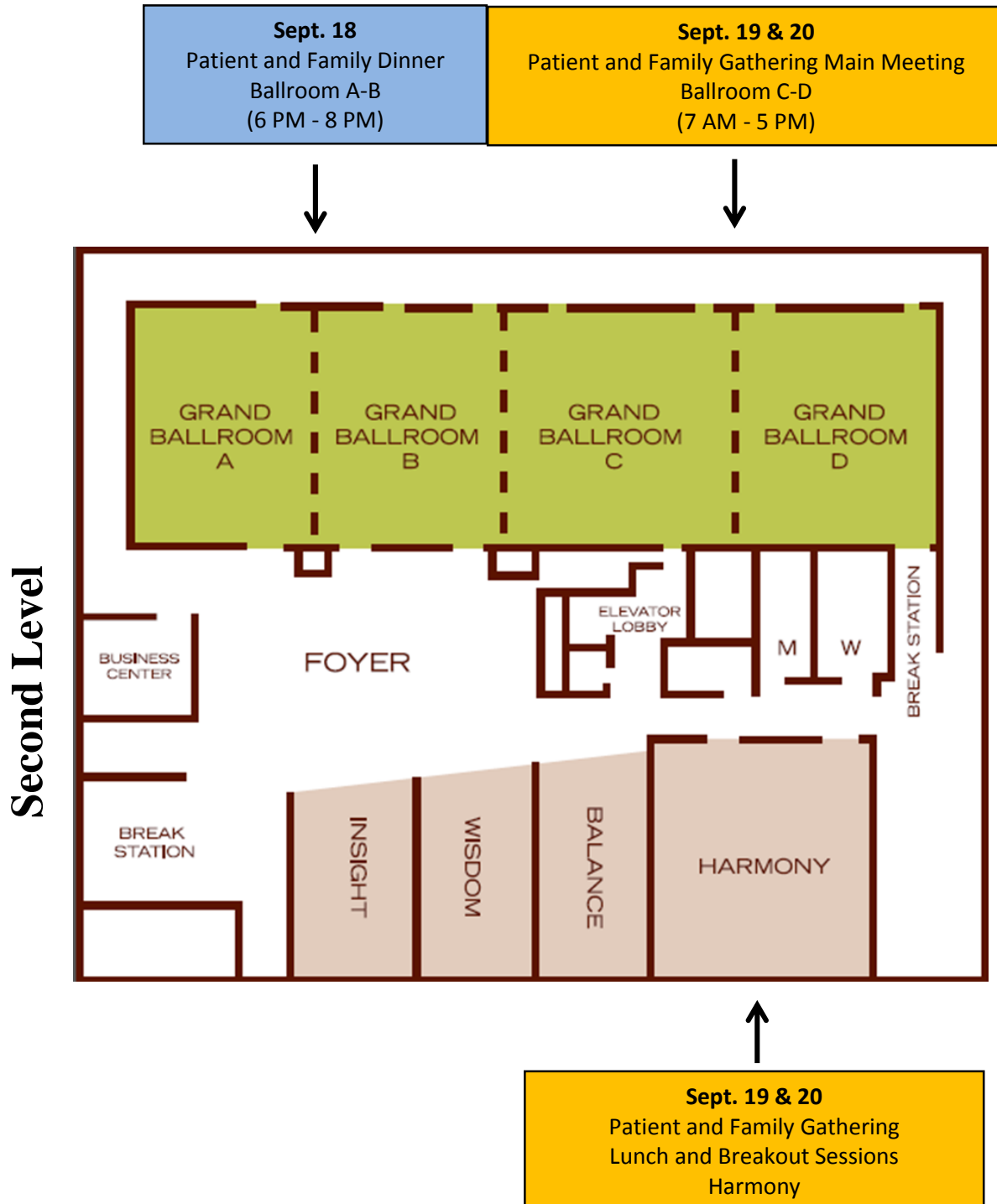
| 2014 Agenda | | | | |
|-------------------------------------|------------------|---|---|---|
| ECD-GA Patient and Family Gathering | | | | |
| September 18 & 19, 2014 | | | | |
| Date | Time | Ballroom AB | | |
| Sept 18, 2014 | 5:00 – 6:00 pm | Pre-registration | | |
| | 6:00 – 8:00 pm | Social Dinner | | |
| Sep 19, 2014 | Time | Ball Room CD | Harmony Room | Wisdom Room |
| | 7:00 – 8:00 am | ----- | Breakfast | ----- |
| | 8:00 – 8:30 | Rare Diseases and the National Institutes of Hope <u>William Gahl, MD, PhD</u> Geneticist, NIH | Space available for caregiver group interactions | Space available for small group interactions |
| | 8:30 – 9:30 am | ECD Treatment Panel <u>Mark Heaney, MD, PhD</u> Hematologist & Oncologist, Columbia | | |
| | 9:30 – 10:30 am | Current ECD Studies/ Research Panel <u>Juvianee Estrada-Veras, MD</u> Geneticist, NIH | | |
| | 10:30 – 11:00 am | Q & A Panel <u>Augusto Vaglio, MD, PhD</u> Nephrologist, Parma University | | |
| | 11:00 – 12:00 pm | Integrative Pain Management <u>Ann Berger, MD</u> Pain and Palliative Care, NIH | | |
| | 12:00 – 1:30 pm | ----- | | |
| | 1:30 – 2:00 pm | Exercise in Erdheim-Chester Disease <u>Ana T. Acevedo, MD</u> Physiatrist, NIH | Space available for caregiver group interactions | |
| | 2:00 – 2:30 pm | Focus on Function: Role of Physical Therapy <u>Zavera Brandon, MPT, DPT, CBIS</u> Physical Therapist, NIH | | |
| | 2:30 – 3:00 pm | Focus on Function: The Role of Occupational Therapy <u>Terri D. Nguyen, MOT, OTR-C</u> Occupational Therapist; NIH | | |
| | 3:00 – 4:00 pm | Understanding the Social Security Disability Program <u>E. Caroline Mason</u> Medical Relations Director, Maryland Disability Determination Services <u>Diana Varela</u> Public Affairs Specialist, Social Security Office | Caring for the Caregiver <u>Ann Berger, MD</u> Pain and Palliative Care, NIH | Obstetric and Gynecologic Health in Patients with ECD <u>Melissa Merideth, MD, MPH</u> Obstetrician/Gynecologist & Geneticist, NIH |
| | 4:00 – 5:00 pm | Oral Manifestations of ECD <u>Pamela Gardner, DMD</u> Doctor of Dental Medicine, NIH | Space available for caregiver group interactions | Space available for small group interactions |
| | 5:00 – 9:00 pm | Ballroom D: ECD Fellowship for Everyone | Caregiver Fellowship | ----- |

B. September 20 Meeting Agenda

| September 20, 2014 | | | | |
|--------------------------|---------------------|---|--|--|
| Date | Time | Ballroom CD | Harmony Room | Wisdom/Balance Room |
| Sept 20, 2014 | 7:00 – 8:00 am | ----- | Breakfast | ----- |
| | 8:00 – 8:30 am | The Social Security Application: Tips & Strategies <u>Susan Robertson, PhD,</u> <u>OTR/L, FAOTA</u> Occupational Therapist, NIH | ----- | The Business of Creating Hope – With You <u>Kathy Brewer</u> President, ECD Global Alliance BOD (Balance Room) |
| | 8:30 – 9:30 am | | Awakening the Spiritual Dimension of Oneself <u>Ann Berger, MD</u> Pain and Palliative Care, NIH | |
| | 9:30 – 10:30 am | Patient Stories & Round Tables <u>Eli Diamond, MD</u> Neuro-oncologist, MSKCC <u>Juvianee Estrada-Veras, MD</u> Geneticist, NIH | Caregiving in the World of ECD <u>Danetta Sloan, PhD</u> Pain and Palliative Care, NIH | Space available for small group interactions |
| | 10:30 – 11:00 am | ECD: The Battle to Find Answers <u>Karla D. Toledo-Frazzini, MD</u> Family & Community Medicine, TTHSC | | |
| | 11:00 – 12:00 pm | Nutrition & Erdheim-Chester Disease <u>Megan Wright, RD</u> Dietitian, NIH | Space available for caregiver group interactions | One-on-one sessions <u>Eli Diamond, MD</u> Neuro-oncologist, MSKCC (Wisdom Room) <u>Juvianee Estrada-Veras, MD</u> Geneticist, NIH (Balance Room) |
| | 12:00 – 1:30 pm | ----- | Lunch | ----- |
| | 1:30 – 2:30 pm | Ideas to Take to Back to Your Medical Team <u>Kevin O'Brien, RN, MS-CRNP</u> Nurse Practitioner, NIH | ----- | One-on-one sessions <u>Eli Diamond, MD</u> Neuro-oncologist, MSKCC (Wisdom Room) <u>Juvianee Estrada-Veras, MD</u> Geneticist, NIH (Balance Room) |
| | 2:30 – 3:30 pm | Get Involved to Create Hope <u>ECD Global Alliance Team</u> | | |
| | 3:30 – 4:00 pm | Pictures of Attendees | ----- | ----- |

C. Map of Patient and Family Gathering Activity Locations

DoubleTree Hotel, Bethesda – Washington, DC



D. 2014 ECD Patient and Family Gathering Panel Members

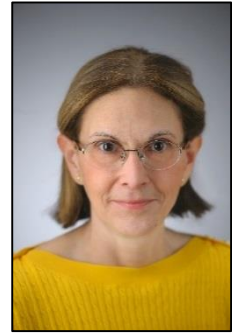
| <u>Panel</u> | <u>ECD Treatment Panel</u> | <u>ECD Studies/ Research Panel</u> | <u>Q&A Panel</u> |
|--------------------------|--|--|---|
| Panel Chair | <u>Mark Heaney, MD, PhD</u> Columbia University Medical Center, US Hematology/Oncology | <u>Juvanee Estrada-Veras, MD</u> National Institutes of Health, US Genetics | <u>Augusto Vaglio, MD</u> University Hospital of Parma, Italy Nephrology |
| Panel Members | <u>Lorenzo Dagna, MD</u> San Raffaele Scientific Institute, Italy Internal Medicine | <u>Giulio Cavalli, MD</u> IRCCS San Raffaele Scientific Institute, Italy Immunology | <u>Lorenzo Dagna, MD</u> San Raffaele Scientific Institute, Italy Internal Medicine |
| | <u>Eli Diamond, MD</u> Memorial Sloan Kettering, US Neuro-oncology | <u>Mark Heaney, MD, PhD</u> Columbia University Medical Center, US Hematology/Oncology | <u>Eli Diamond, MD</u> Memorial Sloan Kettering, US Neuro-oncology |
| | <u>Julien Haroche, MD, PhD</u> Hôpital Pitié-Salpêtrière, APHP, France Internal Medicine | <u>Julien Haroche, MD, PhD</u> Hôpital Pitié-Salpêtrière, APHP, France Internal Medicine | <u>Juvanee Estrada-Veras, MD</u> National Institutes of Health, US Genetics |
| | <u>Peter Hillmen, MD</u> St. James's University Hospital, UK Hematology | <u>Peter Hillmen, MD</u> St. James's University Hospital, UK Hematology | <u>Peter Hillmen, MD</u> St. James's University Hospital, UK Hematology |
| | <u>Augusto Vaglio, MD</u> University Hospital of Parma, Italy Nephrology | <u>David Hyman, MD</u> Memorial Sloan Kettering, US Oncology | <u>David Hyman, MD</u> Memorial Sloan Kettering, US Oncology |
| | ----- | ----- | <u>Andrew Talbot, MD</u> Royal Melbourne Hospital, Australia Nephrology |

E. Presenter Biographies

1. Ana T. Acevedo, MD

Physiatrist, National Institutes of Health; Bethesda, MD, USA

Ana T. Acevedo, MD, a senior staff physiatrist in Rehabilitation Medicine at the NIH Clinical Center, is a Diplomat 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 28 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 joined Rehabilitation Medicine at the NIH Clinical Center in January of 2010 after a lengthy career in the private sector. She currently collaborates with the NHGRI in evaluating patients with rare (Erdheim Chester Disease) and undiagnosed diseases. She is a member of the group collaborating in a research project to understand the impact of Erdheim Chester Disease in the patient's and their caregiver's quality of life.

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National Institutes of Health- Clinical Center
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Title of Presentation: "Exercise in Erdheim-Chester Disease"

The presentation will delineate basic exercise principles and how these apply to patients with Erdheim-Chester Disease.

2. Ann Berger, MD

Pain and Palliative Care; National Institute of Health; Bethesda, MD, USA

Dr. Ann Berger has a B.S. in nursing from New York University, and a MSN in Oncology Nursing from University of Pennsylvania. She completed her medical training at the Medical College of Ohio in Toledo, Ohio. Following medical school, Dr. Berger completed an internship and residency at Hartford Hospital in Connecticut and a Fellowship in medical oncology and pain/palliative care at Yale University in Connecticut. Dr. Berger started a palliative care service, as an Assistant Professor in Medicine and Anesthesiology.



As an Assistant Professor in medicine and anesthesiology at Cooper Hospital/University Medicine and Dentistry in New Jersey, Dr. Berger founded her second successful palliative care service. There, her service was actively involved in the care of patients and in education and research during her four year tenure. She initiated a palliative care course to medical students, residents and Fellows, and utilized her expertise while chairing the ethics committee. Dr. Berger also served as Medical Director of Lighthouse Hospice and as Director of Supportive Care Services at Cooper Hospital/University Medicine and Dentistry in New Jersey. Currently, Dr. Berger is chief of the Pain and Palliative Care Service at the National Institutes of Health, Clinical Center, where she has clinical, teaching, research, and administrative responsibilities.

Nationally, Dr. Berger has been involved with many activities including chair of the National Institutes of Health Clinical Center Pain and Palliative Care Collaborative Working Group, member of the steering committee for the National Palliative Care Consensus Project, and has been on the planning committee to improve quality of end of life care in conjunction with the Washington Area Geriatric Education, RAND Center to improve care of the dying, and DC Partnership to improve end of life care. On a community level Dr. Berger is a co-facilitator of a healing service at her synagogue. Internationally, she has been involved in the All-Ireland Fatigue Coalition, the Mid-Eastern Cancer Consortium, and the Croatian cancer consortium. She has received numerous awards for her work.

Dr. Berger is Senior Editor of the major palliative care textbook, *Principles and Practice of Supportive Oncology*, published by Lippincott-Raven in 1998, as well as senior editor of *Principles and Practice of Palliative Care and Supportive Oncology*, second, third edition last published in 2006, and the 4th edition published in 2013. Since 2004, Dr. Berger had several new books published: *Cancer Pain: A Bedside Approach*, *Chemotherapy-induced Nausea and Vomiting*, *Handbook of Supportive Oncology*- all three for health care professionals, and *Myths and Facts of Cancer Fatigue* for the patient with cancer as well as *Myths and Facts about Chronic and Cancer Pain* published. Dr. Berger has also published her first book for lay people-*Healing Pain*, by Rodale.

Contact information:

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Chief Pain and Palliative Care
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Titles of Presentations:

1. "Integrative Pain Management"
2. "Caring for the Caregiver"
3. "Awakening the Spiritual Dimension of Oneself"

3. Zavera Ranji Brandon MPT, DPT, CBIS
Physical Therapist; National Institutes of Health/Clinical Center; Bethesda, MD, USA

Dr. Brandon has her masters and doctorate in Physical Therapy. She is also a certified brain injury specialist with a specialty in neuromuscular diseases. She is currently practicing at the National Institutes of Health in Bethesda, MD. She has evaluated and treated patients with ECD through the natural history study. She is blessed to have 2 wonderful children, ages 3 and 5.



Contact information:

Zavera Brandon
Building 10, CRC Rm 1-2452NE
10 Center Drive
Bethesda, MD 20892
(301)496-4733

Title of Presentation: “Focus on Function: Role of Physical Therapy”

The presentation’s key points will cover:

1. PT role
2. PT interventions
 - i) Strengthening/conditioning: exercise, weights
 - ii) Balance/Walking
 - iii) Walking aides: walkers, rollators, canes, crutches
 - iv) Safety/fall precautions
 - v) Caregiver training
 - vi) Referrals for community resources: local gyms, water exercise, home programs, outpatient clinics

4. Eli Diamond, MD
Neuro-Oncology, Neurology; Memorial Sloan Kettering Cancer Center; New York, NY, USA

Eli Diamond, MD, is a neuro-oncologist who specializes in the care of patients with brain tumors and ECD, along with the neurologic complications of cancer. He works together with neurosurgeons and radiation oncologists to provide the highest quality medical treatment and supportive care for patients with gliomas and glioblastomas, primary central nervous system lymphomas (brain and spinal cord), ependymomas, and other types of brain tumors. Together with his colleagues in the Memorial Sloan Kettering Counseling Center, he performs clinical research about quality of life, symptom management, and patient-physician communication for patients with brain tumors.



Contact information:

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Titles of Presentations/Discussions:

1. “Patient Stories & Round Tables”
2. “One-on-One Sessions”

5. 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.

Contact information:

Juvianee Estrada-Veras, MD
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National Institutes of Health
10 Center Drive, Bldg. 10, CRC- Room 3-2551
Bethesda, MD 20892-1851 USA
(301)451-7963
juvianee.estrada-veras@nih.gov

Titles of Presentations/Discussions:

1. "Current ECD Studies/ Research Panel"-Panel Chair
2. "Patient Stories & Round Tables"
3. "One-on-One Sessions"

6. William Gahl, MD, PhD
Genetics, NIH; Bethesda, MD, USA

Dr. William A. Gahl, MD, PhD, received his undergraduate degree from MIT in 1972 and his MD and PhD from the University of Wisconsin. He completed a residency in pediatrics at the University of Wisconsin and a postdoctoral fellowship in genetics at the National Institutes of Health.



Dr. Gahl is certified in Pediatrics, Clinical Genetics, and Clinical Biochemical Genetics. He is a past member of the Board of Directors of the American Board of Medical Genetics, past president of the Society for Inherited Metabolic Disorders, and a member of the American Society for Clinical Investigation and the Association of American Physicians. Dr. Gahl is an international expert in cystinosis, Hermansky-Pudlak syndrome, alkaptonuria, and disorders of free sialic acid metabolism. He is currently Clinical Director of the National Human Genome Research Institute, Director of the intramural program of the Office of Rare Diseases, and Director of the NIH Undiagnosed Diseases Program. Dr. Gahl is a recipient of the Dr. Nathan Davis Award for Outstanding Government Service from the American Medical Association and the 2011 Service to America Medal in Science and the Environment.

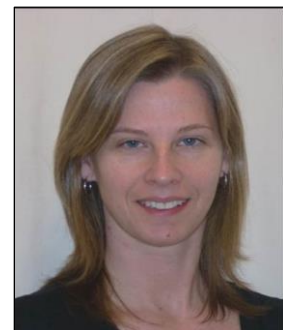
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bgahl@helix.nih.gov

Title of Presentation: “Rare Diseases and the National Institutes of Hope”

7. Pamela Gardner, DMD
Chief, Dental Consult Services; NIH; Bethesda, MD, USA

Dr. Gardner is a Senior Staff Clinician and Chief of Dental Consult Service at the National Institute of Dental and Craniofacial Research/Division of Intramural Research Clinical Research Core. She specializes in Dentistry, Oral Medicine. She has evaluated ECD patients participating in the Natural History Protocol at the NIH.



Contact Information:

Pamela Gardner, DMD
National Institutes of Health
10 Center Drive
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Title of Presentation: “Oral Manifestations of ECD”

Disease specific oral manifestations have been identified in the NIH Erdheim Chester Disease Natural History Protocol population. This presentation will identify these oral findings as well as review clinical management strategies for ECD related dental health issues.

8. Mark Heaney, MD, PhD
Hematology and Oncology, Columbia University Medical Center, New York, NY, USA

Dr. Mark Heaney received his undergraduate education at Harvard and graduate education at the University of Virginia where he received an M.D. and a Ph.D. in microbiology. After Internal Medicine residency at SUNY Stony Brook, he had fellowship training in Hematology and Medical Oncology at Memorial Sloan-Kettering Cancer Center. Dr. Heaney subsequently joined the faculty at Memorial Sloan-Kettering Cancer Center. As a member of the Leukemia Service for nearly 20 years, Dr. Heaney continued laboratory research, initially studying the cell surface receptors that govern white blood cell development and leukemia cell growth. More recently, he has focused on metabolic differences between leukemia cells and normal cells that can provide insight into how leukemia's behave in the individual patient and how they respond to treatment. His finding that vitamin C has the potential to blunt the beneficial effects of chemotherapy has been widely cited.



Dr. Heaney has also been an active clinical investigator. He has been the Principal Investigator of many clinical trials that have aimed at developing new treatments for leukemia. In particular, he has focused on new treatments of the myeloproliferative neoplasms, primary myelofibrosis, polycythemia vera and essential thrombocythemia, but has also studied new treatments for chronic myeloid leukemia, mastocytosis and Langerhans cell histiocytosis in keeping with his clinical expertise in rare blood cancers. His expertise has also led him to treat a number of ECD patients and to an interest in ECD research.

Dr. Heaney joined the faculty at CUMC in January, 2013. He has continued his commitment to caring for patients with blood cancers, developing new treatments including cutting edge clinical trials, and laboratory research that concentrates on translating discoveries from the bench to the bedside.

Contact Information:

Dr. Mark Heaney
Herbert Irving Pavilion, Garden
161 Fort Washington Ave at W. 165th St.
New York, NY
(212)305-5098

Panel Chair: "ECD Treatment Panel"

9. Caroline Mason

Medical Relations Director; Maryland Disability Determination Services, MD, USA

Caroline received her BA from Salisbury State University. She started her career providing direct client services in the rehabilitation field. She moved to indirect client services with the Maryland Disability Determination Services in 1995. Currently as the Medical Relations Director she serves as the liaison for community and advocacy groups, disseminating information about Social Security Administration's disability programs. Caroline was a recipient of a Governor's Citation for her participation in Maryland's SSI/SSDI Outreach, Access and Recovery (SOAR) Program.



Contact information:

Caroline Mason
Maryland Disability Determination Services
170 W Ridgely Rd. Ste. 310
Lutherville, MD 21093-5127
(410) 308-4336
elizabeth.c.mason@ssa.gov

Title of Presentation: Understanding the Social Security Disability Program

This presentation will discuss the services that the Social Security Administration and Maryland Disability Determination Services provide to Maryland children and adults with disabilities. Participants will understand eligibility requirements for Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) benefits. This information will provide ECD patients, their families and advocates with the knowledge and tools to assist in navigating the application and overall disability process.

10. Melissa Merideth, MD, MPH

Obstetrician/Gynecologist & Geneticist, National Institutes of Health; Bethesda, MD, USA

Dr. Melissa Merideth is an OB/GYN and Geneticist who has expertise and interest in caring for women with rare diseases. She works at the National Institutes of Health (NIH) in Bethesda, Maryland. Dr. Merideth completed medical school and graduate school at Johns Hopkins University in 1997, finished her ob/gyn residency at the Mayo Clinic in 2001, and after practicing at the Mayo Clinic in Arizona for two years, headed to the NIH in 2003, where she completed fellowships in Clinical and Biochemical Genetics. She works as a gynecologist and geneticist at the National Human Genome Research Institute providing clinical care for patients at the NIH and doing clinical research. Dr. Merideth is board certified in Obstetrics/Gynecology, Clinical Genetics and Biochemical Genetics. She is also a Captain in the United States Public Health Service and helps provide medical care for public health emergencies. She has enjoyed the opportunity to see patients with Erdheim Chester Disease who are undergoing evaluation in the Natural History Protocol at the NIH.



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10 Center Drive, Bdg. 10, 10C103, MSC 1851
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(301) 496-9101

Title of Presentation: “Obstetric and Gynecologic Health in Patients with Erdheim Chester Disease”

This discussion will cover the obstetrics and gynecologic issues in patients with Erdheim Chester Disease who have undergone gynecologic evaluations as part of the natural history protocol at the NIH.

11. Terri D. Nguyen, MOT, OTR-C

Occupational Therapist, National Institutes of Health; Bethesda, MD, USA

Terri D. Nguyen has been living in the Washington metropolitan area for about 30 years. Her work at the NIH has centered on helping individuals with visual deficits function more successfully in the community and in daily living within the home.



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Building 10, CRC Rm 1-1468 1NE
Bethesda, MD 20892 - 1604
(301) 496-4733

Title of Presentation: “Focus on Function: The Role of Occupational Therapy”

The presentation’s key points will cover:

1. Evaluation and Treatment: an Occupational Therapy Perspective
 - i) Role of OT/ Unique focus on function for daily life activities
2. Occupational Therapy Interventions
 - i) Compensatory and Adaptive Strategies
 - ii) Preventive Measures
 - iii) Family Training and Community Resources

12. Kevin O'Brien RN, MS-CRNP

Associate Clinical Investigator, National Institutes of Health; Bethesda, MD, USA

Kevin earned his Bachelor of Science from Johns Hopkins and a Master’s/Nurse Practitioner’s Degree from the University of Maryland. Currently, he works with ECD patients in the natural study research trial in the Human Biochemical Genetics division of the Medical Genetics Branch.



Before coming to the NIH, he worked in internal medicine and primary care. Kevin also has training in psychiatric nursing

In his free time, he enjoys spending time with family, pursuing church related activities, hiking, gardening, and reading.

Contact Information:

Kevin O'Brien, RN, MS-CRNP
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Title of Presentation: “Ideas to Take Back to Your Medical Team”

13. Susan Robertson, PhD, OTR/L, FAOTA
Rehabilitation Medicine Department; NIH; Bethesda, MD, USA

Dr. Susan C. Robertson is an occupational therapist with a Bachelor of Science, Psychology and Anthropology, a Master of Science in Occupational Therapy, and a PhD in Human Development. She practices her specialty in mental health at the National Institutes of Health. She has participated in the interviewing of ECD patients and their caregivers that have visited the NIH.

Contact information:

Susan Robertson, PhD
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10 Center Drive, MSC 1604
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Title of Presentation: "The Social Security Application: Tips and Strategies"

The presentation's key points will cover:

1. ECD and Financial constraints
2. Social Security Programs
 - i) SSDI vs SSI eligibility criteria
 - ii) Application Process
 - iii) First phase: Application, Adult Disability Report, and Medical Authorization Form
 - iv) Second phase: Work History Report and Function Report
 - v) Medical Eligibility
 - vi) Post-eligibility issues
 - vii) Appeals

14. Danetta E. Sloan PhD, MSW
NIH Research, Clinical Center Pain and Palliative Care (PPCS)

Dr. Danetta E. Sloan works in research at the NIH clinical center under the mentorship of Dr. Ann Berger, Chief of the Pain and Palliative Care Consult Service. In the role as research fellow, Dr. Sloan provides support to the Erdheim-Chester Disease protocol. In addition to this role, she is a clinical social worker and grief counselor for a local non-profit hospice in Washington, DC and Maryland. Mrs. Sloan is a medical social worker that has 9 years of experience in facilitating grief and loss support groups as well as individual counseling in the area of palliative care and hospice. She received her B.S. degree in General Psychology and Master of Arts in Experimental Psychology both from Towson University in Towson, Maryland. She furthered her education at The Catholic University of America, National School of Social Services, where she completed a Masters in Social Work, and completed the Doctoral Program for Clinical Social Work.



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Title of Presentation: "Caregiving in the World of ECD"

Topic discussions will include:

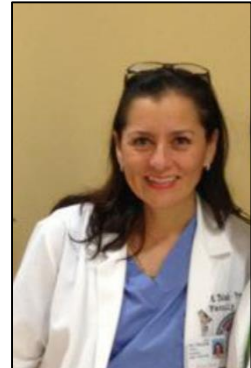
1. Communicating with your Care Team
2. Adjusting to Relationship/Role Changes
3. Taking Time for Self Care
4. How Do I Face the Unknown

15. Karla D. Toledo-Frazzini, MD

Family Medicine and Community Medicine, Texas Tech Health Sciences Center at the Permian Basin, Odessa, Texas

Dr. Karla D. Toledo-Frazzini is a 3rd year Family Medicine Physician Resident, a mother of 3 boys (2, 6, and 12) and a wife of great man, who has been battling a set of vague and unclear multi-system symptoms for more than 5 years.

As a wife, it has been very painful having a family member with complaints that no doctor could explain for years; as a physician, it has been a frustrating long journey, trying to accommodate scattered symptoms and signs into one illness. It has been challenging putting the pieces together to finally solve the puzzle, the puzzle named Erdheim-Chester Disease. She performed personal research to find the answers to her husband's non diagnosed illness to finally reach the correct diagnosis of ECD.



Dr. Toledo-Frazzini would like for patients with ECD to know that they are not alone, that there are physicians trying to help; those that keep doing research day after day. They are trying as hard as they can to find answers and a cure for this rare disease.

Dr. Toledo-Frazzini would like for families to know that physicians understand their pain and frustration of not having definite answers to all of their questions. The physicians try to do their best for their patients and to improve their quality of life. She wants the families and patients to understand how some physicians are going through the same things.

Her hope is for the patients and their families to speak up, to keep looking and to not give up hope. Because we can, all together find answers to all the questions we have; and we can enjoy life, one day at the time.

Contact information:

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Texas Tech Family Practice Center
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Odessa, TX 79763
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Title of presentation: "ECD, The Battle to Find Answers"

16. 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.

Contact information:

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Panel Chair: "Q & A Panel with Medical Professionals"

17. Diana Verela

Public Affairs Specialist, Social Security Office; Silver Spring, MD, USA

Diana Verela began her career with Social Security Administration as a Bilingual Service Representative in May 1995. She has held Claims Representative and Field Representative positions. She was appointed as a Bilingual Public Affairs Specialist in January 2003 to promote understanding of Social Security Programs in the Non- English Speaking Communities of the Washington Metropolitan area, as well as the American Public at large.



Title of Presentation: “Understanding the Social Security Disability Program”

This presentation will discuss the services that the Social Security Administration and Maryland Disability Determination Services provide to Maryland children and adults with disabilities. Participants will understand eligibility requirements for Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) benefits. This information will provide ECD patients, their families and advocates with the knowledge and tools to assist in navigating the application and overall disability process.

Contact information:

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(410) 308-4336

18. Megan Wright RD, CNSC

Certified Nutrition Support Clinician, National Institute of Health Clinical Center; Bethesda, MD, USA

Megan is a Clinical Research Dietitian at the National Institutes of Health Clinical Center. She graduated from North Carolina State University with a Bachelor of Science in Nutrition. She then completed her Dietetic Internship at Meredith College which included clinical practice at University of North Carolina Hospitals. Megan has been working as a clinical dietitian for the past 5 years and is a Certified Nutrition Support Clinician (CNSC). She began her career at the NIH Clinical Center 5 months ago and has been working with Erdheim-Chester Disease patients ever since. Megan enjoys cooking, practicing yoga, and traveling.



Contact information:

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Title of presentation: “Nutrition and Erdheim-Chester Disease”

This presentation will cover general healthy nutrition and how it relates to Erdheim-Chester Disease. It will review management of side effects associated with ECD and treatment. The presentation will also discuss why it is important to take caution before starting alternative nutrition supplements.

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“Supporting those affected by Erdheim-Chester Disease”



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