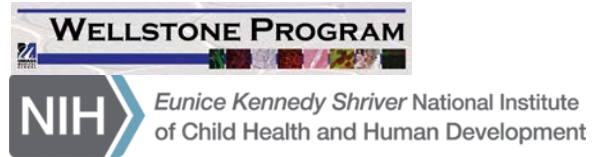


FSH Society 2016 Patient Connect, November 11-12, 2016

Westin Copley Place Hotel, Boston, Massachusetts

Sponsored by:



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Dear Friends,

Welcome to the 2016 FSHD Patient Connect, our international patient-researcher networking conference for Facioscapulohumeral Muscular Dystrophy (FSHD). Thank you for your commitment in working with the FSH Society and the patient, research and clinical communities to find solutions for FSHD. The FSH Society is a world leader in combating muscular dystrophy. It has provided nearly \$7 million in grants to pioneering FSHD research. We have provided education worldwide on FSHD and created an international collaborative network of patients and researchers. This year's program demonstrates the fruits of an ongoing, challenging, and productive dialogue that the FSH Society has facilitated over the years.

During the next two days, you will hear from distinguished speakers on clinical and research topics related to FSHD. In addition to the lecturers and moderators, we have many prominent FSHD researchers and clinicians in the room with us, and we encourage you to reach out and say hello to those sitting next to you, across from you and around the room. Our good colleagues and friends are here to offer support and gain insights. Each new day brings new knowledge and new technologies that will help make for a longer and higher quality of life. We are now 6,000 families strong and our shared experience and constituency allows us to clearly see where the opportunities are and where the deficits are in care for those with FSHD.

Many of you know the extraordinary impact the FSH Society has had in advocacy, education, research, networking, and helping promote solutions. The FSH Society's efforts have led to increased funding in the United States and abroad. It was a key participant in drafting the Muscular Dystrophy Community Assistance Research and Education Act of 2001 (MD CARE Act), which in the United States mandates research and investigation into all forms of Muscular Dystrophy. The MD CARE Act has helped provide hundreds of millions of dollars in additional NIH funding since its inception and this in turn has fostered billions of dollars in non-federal funding into muscular dystrophy in the past 15 years.

These successes notwithstanding, it remains a daily challenge to attain the funds we need to survive and grow. The Society's work of the past 25 years has been largely driven by the passion, dedication and extremely long hours given by a very small group of people committed to change. Prof. David Housman, Chairman of the FSH Society Scientific Advisory Board (SAB), and his colleagues on the SAB have given selflessly of themselves, their knowledge and their time at no charge to bring about insight into FSHD to help those suffering from the disease. Our colleagues on the Board of Directors work countless hours without remuneration to guide the organization and fundraise. We stand on the brink of developing new treatments, and now we need all of you more than ever, to help reach our goals. We need you to volunteer for research and raise awareness. And we need your help to raise millions of dollars to sustain the pace of research and prepare for future clinical trials. Please, support the Society generously, and urge friends, family, business colleagues and your communities to do the same.

The FSH Society wishes to thank the 2016 FSHD Patient Connect speakers and all attendees for their contributions to the success of this meeting. We thank our sponsors, including: Acceleron, Association Francaise contre les Myopathies, aTyr Pharma, Biomarin, Cytokinetics, Facio Therapies, FSH Society, Fulcrum Therapeutics, Genea Biocells, Genzyme-Sanofi, the Hecht and Cohen families, Idera, Mouse Specifics, Muscular Dystrophy Campaign (UK), U.S. DHHS NIH University of Massachusetts Medical School Senator Paul Wellstone MD Cooperative Research for FSHD, Quintiles, Sarepta, Ultragenyx, and Wendy and Wayne Shack for helping to make this meeting possible. We especially thank all of the attendees for supporting this meeting through gifts and registrations and by actively participating.

You are not alone in living with FSHD. Many talented people are working hard to solve and treat FSHD and advocate for the well-being of all who live with this condition. We hope you feel empowered by the patient-patient and patient-researcher interactions. The Society is here for you and we count on you to ask others to support the Society and allow us to continue the excellent research and programs.

Sincerely,

William R. Lewis, Sr., M.D.
Chairman, Board of Directors
FSH Society

Daniel Paul Perez
President & CEO
FSH Society

June Kinoshita
Executive Director
FSH Society



2016 FSHD PatientConnect

The FSH Society's International Network Meeting for
FSHD Patients, Clinicians and Researchers

Friday-Saturday, November 11-12, 2016

The Westin Copley Place Hotel

10 Huntington Avenue, Boston, Massachusetts 02116

AGENDA

Thursday, November 10

9:00 am -5:00 pm Registration. Essex Ballroom Foyer.

6:30 – 9:00 pm Informal meet-up. Westin Copley Place Hotel lobby bar.

Friday, November 11

9:00 am–1:00 pm **Registration.** Essex Ballroom Foyer.

1:00—1:05 pm **Welcome.** Essex Ballroom.

1:05—2:30 pm **Understanding FSHD**

- 1:05—1:30. FSHD Science 101. Alexandra Belayew, PhD
- 1:30—1:50. Genetics and genetic testing. Silvere van der Maarel, PhD
- 1:50—2:10. How FSHD affects your body and health. Kathryn Wagner, MD
- 2:10—3:00. Getting to know you (facilitated discussion). Claudia Ordonez, MD

3:00-3:15 **Break**

3:15—5:00 pm **Prospects for treating FSHD**

- 3:15—3:45. Treatment strategies (panel): Peter Jones, PhD; Yi-Wen Chen, PhD; Scott Harper, PhD
- 3:45—4:00. Getting ready for clinical trials. Jeff Statland, MD
- 4:00—4:15. Clinical trials: current and impending. Rabi Tawil, MD
- 4:15—4:30. FSHD tissue donation registry. Deneé Tidwell.
- 4:30—5:00. Q&A session

5:00 pm **Adjourn for the day.**

6:00 pm **Gala reception.*** Essex Ballroom Foyer.

7:00 pm **CureFSHD Gala.*** Dinner, awards, concert.

**Separate gala ticket required.*

Saturday, November 12

8:00 am **Registration.** Breakfast served. Essex Ballroom Foyer.

8:45—9:00 am **Welcome.**

Breakout sessions: Please consult speaker biographies for background.

9:00—10:00 am **Concurrent Breakout Sessions 1A.**

- Physical Therapy & Exercise (Katy Eichinger, PhD). Essex ballroom.
- Respiratory health (Nicholas Hill, MD). St. George A.
- Living well: Life with FSHD (Ora Prilleltensky, EdD). St. George B.
- Loving well: Living with a person with FSHD (Isaac Prilleltensky, PhD). St. George C.
- Pregnancy & women's health (Kelly Minks, MS, CGC). St. George D.

10:00-10:30 am **Break**

10:30-11:30 am **Concurrent Breakout Sessions 1B (repeat of 1A)**

- Physical Therapy & Exercise (Katy Eichinger, PhD). Essex Ballroom.
- Respiratory health (Nicholas Hill, MD). St. George A.
- Living well: Life with FSHD (Ora Prilleltensky, EdD). St. George B.
- Loving well: Living with a person with FSHD (Isaac Prilleltensky, PhD). St. George C.
- Pregnancy & women's health (Kelly Minks, MS, CGC). St. George D.

11:30 pm – 1:00 pm **Lunch (included in registration)**
What's your story? Getting to the next level with advocacy.

1:00 – 2:00 pm **Concurrent Breakout Session 2A**

- Waking up your muscles (Lynnette Rasmussen, TBC). Essex ballroom.
- Ask the scientist (Peter Jones PhD, Lawrence Hayward MD). St. George A.
- Managing pain & chronic fatigue (Katy Eichinger, PhD). St. George B.
- Living well and loving well: Meeting everyone's needs (Ora Prilleltensky, EdD & Isaac Prilleltensky, PhD). St. George c.
- For the newly diagnosed & mildly affected (Carol Birnbaum, MD). St. George D.

2:00 – 2:30 pm **Break**

2:30 – 3:30 pm	Concurrent Breakout Session 2B <ul style="list-style-type: none">• Waking up your muscles (Lynnette Rasmussen, TBC). Essex ballroom.• Focus group with Acceleron Pharma. St. George B• Ask the scientist (Peter Jones PhD, Lawrence Hayward MD). St. George C.• For the newly diagnosed & mildly affected (Carol Birnbaum, MD). St. George D.
3:30 – 4:30 pm	Fundraising and development brainstorming workshop. Beth Johnston, Development Officer + Development Committee. Essex Ballroom.
3:30 – 4:30 pm	Social hour. Essex Ballroom foyer.
4:30 – 5:00 pm	Finale. Essex Ballroom. Assessments, feedback and farewell.

Photography: Staff and participants will be taking photos during the meetings for use in FSH Society print and electronic publications. If you do not wish a photo/video of yourself to be used in this manner, please move out of the picture and/or give one of the Society's staff a written note with this instruction.

Patient Connect Speakers for Friday, November 11, 2016

Alexandra Belayew, PhD
Professor Emeritus
Department of Molecular
Biology
University of Mons
Mons, Belgium

The DUX4 gene that maps in the D4Z4 repeated element was discovered in 1996 by Dr. Belayew's group in Prof. D. Collen's Research Center at the University of Leuven, Belgium (collaborations Drs. R. Frants and J. Hewitt). The project was continued in her own laboratory established at the University of Mons in Sept 1999 with co-PI Frédérique Coppée. The group was a pioneer in detecting the very low abundance DUX4 mRNA and protein in FSHD muscle cells, in showing its cell toxicity and proposing it caused a gene deregulation cascade (collaborations Drs. A. Rosa, Y.W. Chen, and M. Kyba). The Belayew/Coppée lab has developed antisense agents (collaboration Dr. S. Wilton) to prevent DUX4 protein expression and the resulting atrophic FSHD myotubes observed in cultures. Other agents can prevent the expression of similar DUX4c that is involved in muscle regeneration and activated in FSHD. The group recently found (collaboration Dr. S. Harper) DUX4/4c associated with proteins involved in building the muscle cell skeleton, a new function that could explain the disorganized FSHD myotubes also observed in culture. Further studies of these new functions should thus lead to a better understanding of the pathology.



Yi-Wen Chen, DVM, PhD
Associate Professor
Department of Integrative
Systems Biology, George
Washington University
Center for Genetic
Medicine Research,
Children's National Medical
Center
Washington, DC 20010

Dr. Chen's research interests focus on the pathophysiological mechanisms of muscle disorders and molecular responses to muscle disuse and rehabilitation. She started her research in FSHD by studying molecular mechanisms of the disease. In collaboration with Dr. Sara Winokur, the collaborative group first reported genome-wide gene expression changes in FSHD and proposed potential mechanisms of the disease. Subsequently, in collaboration with Dr. Alexandra Belayew, the group demonstrated aberrant expression of double homeobox protein 4 (DUX4) in FSHD and reported the polyadenylation signal of DUX4 in the genomic region adjacent to the last DUX4 copy. Her group then examined downstream regulatory targets and pathways of DUX4, regulatory roles of miRNA in FSHD, and gene regulatory proteins that modulate DUX4 expression. Her recent research activities focus on developing therapeutic strategies and identifying biomarkers for FSHD. She is currently the co-chair of a multicenter collaborative study on the clinical features, expression profiling, and quality of life of pediatric fascioscapulohumeral muscular dystrophy originally supported by the FSH Society.



Scott Q. Harper, Ph.D.
Associate Professor of
Pediatrics
The Ohio State University
College of Medicine
Principal Investigator, Center
for Gene Therapy,
The Research Institute at
Nationwide Children's
Hospital
Columbus, Ohio

Dr. Scott Harper is a native of Saginaw, Michigan. He joined the U.S. Navy at age 19 and served in the Navy Reserves while earning a Bachelor of Science degree from Saginaw Valley State University, where he studied Biology and Chemistry. In 1996, he entered graduate school in the Cellular and Molecular Biology Program at the University of Michigan, and eventually earned a PhD in 2002. His thesis work was focused on using mice to develop a gene therapy approach to treat Duchenne Muscular Dystrophy (DMD), a strategy which is now being tested in clinical trials almost 15 years later. Dr. Harper then moved to the University of Iowa to do a post-doctoral research fellowship, where he worked on pioneering RNA interference (RNAi) gene therapies to treat dominant neurodegenerative diseases, including Huntington's Disease (HD). Beginning in 2007, Dr. Harper began combining his interests in muscle gene therapy and RNA interference technologies to develop his own independent research program, as a faculty member with a joint appointment at the Ohio State University College of Medicine and Principal Investigator in the Center for Gene Therapy at Nationwide Children's Hospital in Columbus, Ohio. The Harper lab has recently grown to 8 members, all with primary focus on understanding the biology of the DUX4 gene and developing models and therapies for FSHD.



Jeffrey Statland, MD
Assistant Professor of
Neurology
University of Kansas Medical
Center
Kansas City, Kansas

Dr. Jeffrey Statland has both clinical and research training in neuromuscular diseases, with a primary research interest in FSHD. Dr. Statland's current research includes an FSHD disease-specific patient reported health inventory, an FSHD-specific functional rating scale, approaches for analyzing dynamic motion, and the electrical impedance myography. With Dr. Rabi Tawil at the University of Rochester Medical Center, he has established the FSHD Clinical Trial Research Network, a group of 7 FSHD specialty centers across the United States with a common goal of hastening drug development for FSHD. "By working hand in hand with the basic scientists and our international collaborators we not only learn about how to measure the disease progression in FSHD, but we also gain insight into the molecular underpinnings of FSHD, and the corresponding clinical expression in patients. Together we can develop the institutional infrastructure and tools to run high quality, efficient clinical trials."



Rabi Tawil, MD

Professor of Neurology
University of Rochester Medical
Center
Director of the Fields Center for
FSHD Research
Rochester, New York

Rabi Tawil, MD. Professor of Neurology, University of Rochester Medical Center, Director of the Fields Center. Dr. Tawil is a clinician-researcher with long standing involvement in FSHD (FSHD dystrophy) research. His FSHD research has included an extensive natural history study, studies correlating the genetic defect and the clinical severity, and the first controlled therapeutic trials in this condition. He has organized and chaired several international FSHD meetings and has served on the FSH Society scientific advisory board for ten years. He is also a Co-Investigator for the National Registry FSHD Patients and Family Members, based at the University of Rochester, instituted to link patients with investigators to facilitate research into these diseases. Dr. Tawil's recent work helped establish FSHD2 as a separate but converging disease entity. Additionally, he has spearheaded workshops to establish standards of care in FSHD as well as to establish the necessary tools for FSHD clinical trials. With the crucial help of the FSHD patient community, Dr. Tawil has established the largest FSHD bio-repository in the world. This repository of well-characterized biological samples was essential in facilitating the recent molecular discoveries by Drs. van der Maarel, Tapscott and Tawil.



Deneé Tidwell

Manager, Partnership
Development
National Disease Research
Interchange (NDRI)
Philadelphia, Pennsylvania

Ms. Tidwell has been with the National Disease Research Interchange (NDRI) since 2013 and has had positions in the operations and business development sectors of the company. In 2014 she was named Project Manager, Partnership Development. At NDRI, Ms. Tidwell is responsible for providing support for all aspects of the development and maintenance of partnerships with corporate, government, philanthropic and education entities. Ms. Tidwell is responsible for project management activities regarding the FSH Society-NDRI FSHD Tissue Donation Registry's initiation and implementation. Ms. Tidwell holds a B.S in Civil Engineering from the University of Virginia.

**Silvère van der Maarel, PhD**

Professor of Medical Epigenetics, Head, Department of Human Genetics
Leiden University Medical Center
Leiden, The Netherlands
Co-Director, Fields Center for FSHD Research, University of Rochester Medical Center
Rochester, New York

Prof. Dr. Ir. Silvère M. van der Maarel was trained as a Human Geneticist at the Radboud University Nijmegen Medical Center in the Netherlands. In 1997, Prof. van der Maarel joined the Department of Human Genetics in Leiden (LUMC, the Netherlands). In 2006, he was appointed Professor of Medical Epigenetics and from 2012 he has chaired the Department of Human Genetics. Prof. van der Maarel's main interest is the genetic and epigenetic basis of facioscapulohumeral muscular dystrophy (FSHD), an adult muscle disease caused by genetic and epigenetic changes in a repetitive DNA structure in the subtelomere of the long arm of chromosome 4. He made seminal contributions to the identification of the unifying genetic mechanism underlying FSHD, including the mechanism explaining the disease susceptibility of a subset of chromosomes 4, and the identification of the disease genes *SMCHD1* and *DNMT3B*. He also studies the genetic and epigenetic mechanisms underlying immunodeficiency, centromeric instability and facial anomalies syndromes (ICF syndrome), a rare primary immunodeficiency caused by mutations in four genes that regulate the chromatin structure of repetitive DNA.

**Kathryn R. Wagner, MD, PhD**

Director, The Center for Genetic Muscle Disorders, Kennedy Krieger Institute
Co-PI, NIH Wellstone Center for FSHD Research
Professor, The Johns Hopkins School of Medicine
Baltimore, Maryland

Dr. Kathryn R. Wagner treats patients with muscular dystrophies in a multidisciplinary clinic, addressing the multiple medical and social issues affecting individuals and families. Dr. Wagner conducts clinical trials and studies in FSHD currently including a bone health study, a biomarker study and a clinical trials outcome measures study. Dr. Wagner's laboratory focuses on developing methods to promote muscle regeneration. A major emphasis of her laboratory has been on modulating myostatin, an endogenous regulator of muscle. Dr. Wagner's laboratory has shown that inhibition of myostatin stimulates muscle stem cells, improving muscle regeneration while reducing fibrosis in animal models of muscular dystrophy. Current efforts include collaborations with industry to combine stem cell and pharmacological therapies for enhanced regeneration. She is an advisor for the FSH Society, Parent Project Muscular Dystrophy and the TREAT-NMD Advisory Committee for Therapeutics.

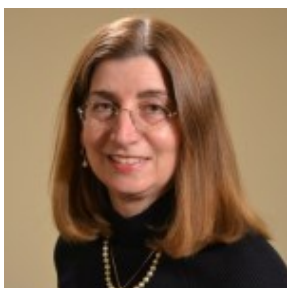
Patient Connect Breakout Session Speakers, November 12, 2016**Thienhuu Nguyen****Jordyn Hanover**

Acceleron Pharma

Cambridge,

Massachusetts

Our FSHD research team is seeking to meet with FSHD patients age 18 or older for a focus group discussion. Caregivers are also welcome to join. The team would like to meet with 4 to 6 patients to better understand the challenges of living with FSHD. Patients (and caregivers) will get the chance to educate researchers and inform the clinical trial design of potential future therapies for FSHD. If interested in participating, please respond to jhanover@acceleronpharma.com with your name, phone, and e-mail. It would also be very helpful if you could provide a brief description of how FSHD has impacted you in your reply. Thank you in advance for your consideration and help.

**Carol S. Birnbaum, MD**

Psychiatrist

Private Practice

Cambridge, Massachusetts

Carol S. Birnbaum, MD, is a psychiatrist in private practice in Cambridge, Massachusetts. She is a tireless advocate for the Society as an advisor and liaison with patients and families. In 2011, Carol lost her mother to complications related to FSHD. She is eager to promote the Society in its search for a cure and to offer support and guidance for patients and their families. Carol is a graduate of Bryn Mawr College and the University of Connecticut School of Medicine. She completed her residency in psychiatry and a fellowship in biological psychiatry at Massachusetts General Hospital, and is a graduate of the Boston Psychoanalytic Society and Institute. She resides in Cambridge, Massachusetts, with her husband Adam, a chef, and two sons.

**Katy Eichinger PT, PhD, DPT, NCS**

Senior Instructor

Neuromuscular Disease Center

University of Rochester Medical Center

Rochester, New York

Katy Eichinger is a physical therapist in the Neuromuscular Disease Center at the University of Rochester Medical Center. She received a Ph.D. in Health Practice Research from the University of Rochester, School of Nursing in 2016, a Doctorate of Physical Therapy from Upstate Medical University in 2007, and a Master of Science degree in Physical Therapy from Springfield College in 1996. She is certified by the American Board of Physical Therapy Specialties in Neurologic Physical Therapy. She is involved in the clinical care individuals with adult and pediatric neuromuscular conditions. She is part of the neuromuscular research team and is involved in natural history studies and clinical trials involving patients with FSHD, Charcot-Marie-Tooth disease, Duchenne muscular dystrophy, and myasthenia gravis. Her interests are in outcome measures, health and wellness, and balance.

**Lawrence J. Hayward, MD, PhD**

Professor of Neurology
Co-Director, FSHD
Multidisciplinary Clinic
University of Massachusetts
Medical School
Worcester, MA 01655

Dr. Hayward is Professor of Neurology at the University of Massachusetts Medical School, where he serves as Co-Director of the UMass multidisciplinary FSH muscular dystrophy clinic. He completed his residency training in Neurology at Massachusetts General Hospital in 1993 and further specialization as a Neuromuscular clinical and research fellow in 1997. Dr. Hayward's research over the past 25 years has focused on defining molecular mechanisms that contribute to neuromuscular diseases, including various myopathies and ALS. He applies expertise in basic muscle biology, cellular and animal modeling, protein biochemistry, and electrophysiology to understand how gene defects cause disease so that more effective treatments can be designed. He collaborates closely with researchers in the Senator Paul D. Wellstone Muscular Dystrophy Cooperative Research Center for FSHD at UMass. In addition to following patients with FSHD, he teaches medical students and house staff in the clinic and in the medical and graduate schools.

**Nicholas Hill, MD**

Chief, Pulmonary, Critical Care
and Sleep Division
Professor, Tufts University
School of Medicine
Boston, Massachusetts

Dr. Hill is a specialist in pulmonary hypertension, mechanical ventilation, noninvasive ventilation, general pulmonology. He has experience managing the respiratory issues of FSHD patients. Dr. Hill is board certified in internal medicine, pulmonary disease, and critical care medicine. He attended Harvard College and Dartmouth Medical School, and did his internships and residency at New England Medical Center and Tufts University School of Medicine. He has been named among America's Top Doctors and the top 1% in his specialty.

**Peter L. Jones, PhD**

Associate Professor
Cell and Developmental Biology
University of Massachusetts
Medical School
Worcester, Massachusetts

Dr. Peter Jones first made his mark in the field of epigenetics as a post-doctoral fellow with Dr. Alan Wolffe at NIH in Bethesda, MD where he identified the connection between DNA methylation, histone modifying enzymes and a repressive chromatin structure. Dr. Jones' interest in FSHD began in 2003 when, as an Assistant Professor at the University of Illinois at Urbana-Champaign, a graduate student who had been recently diagnosed with FSHD introduced him to the disease and the possible role of epigenetics. By 2006 the Jones lab was working full-time on multiple FSHD projects thanks to funding from the FSH Society and NIH. In 2008, Dr. Takako Jones joined the lab full-time, bringing great expertise in developmental, cellular and molecular biology. Currently, the Jones' function as Co-PIs of their lab investigating the epigenetics of FSHD families, studying the mechanisms regulating DUX4 expression in muscle, developing FSHD-like animal models, and identifying new therapeutic approaches for FSHD.

**Kelly Minks, MS, CGC**

Certified Genetic Counselor
Departments of Neurology and
Medicine
University of Rochester
Rochester, New York

Kelly Minks graduated from University of Rochester in 2009 with a Bachelor of Science in Molecular Genetics. In 2011 she graduated from University of North Carolina at Greensboro with a Master of Science in genetic counseling. Following graduation, Minks worked as a prenatal genetic counselor for a private maternal fetal medicine practice in Fort Myers, FL. She is currently a full-time genetic counselor at the University of Rochester Medical Center in the Department of Neurology, Division of Child Neurology and the Department of Medicine, Division of Genetics. She will present findings from research on the impact of pregnancy on women with FSHD, answer your questions about reproductive options for families with FSHD, and facilitate an open discussion on Ob/Gyn health concerns of women with FSHD, a topic that has received inadequate attention by researchers.



Claudia Ordoñez, MD
Chief Medical Officer
Flatley Discovery Lab
Charlestown,
Massachusetts

Dr. Claudia Ordoñez attended Medical School at the University of California San Francisco. She then completed a pediatric residency at Children's Hospital Oakland and a pediatric pulmonary fellowship at the University of California San Francisco. After completing training, she was on faculty at Children's Hospital Boston. She then joined Vertex Pharmaceuticals, where she led the clinical development program for Kalydeco from the First-in-Human study to approval by the FDA and EMA. She then joined Biogen Idec as a Senior Medical Director, where she led the clinical development program for Tecfidera. She currently is Chief Medical Officer at Flatley Discovery Lab, a non-profit biotech company focused on the development of therapies for cystic fibrosis. Dr. Ordonez has experience facilitating conversations between patient advocacy groups and researchers.



Isaac Prilleltensky, Ph.D.
Dean and Professor
Vice Provost for Institutional
Culture
Erwin and Barbara Mautner
Chair in Community Well-Being

Dr Isaac Prilleltensky is dean of the School of Education and Human Development and vice provost for institutional culture at the University of Miami. Isaac holds the inaugural Erwin and Barbara Mautner Chair in Community Well-Being. He has published eight books and over 130 articles and chapters. His interests are in the promotion of well-being in individuals, organizations, and communities; and in the integration of wellness and fairness. He was recipient of the 2011 "Distinguished Contribution to Theory and Research Award" of the Community Psychology Division of the American Psychological Association, and of the 2014 Lifetime Achievement Award in Prevention by the division of Counseling Psychology of APA. Isaac is a vegan, fitness aficionado, and humor writer. Isaac won an award for his humor writing by the National Newspaper Association. His most recent book is *The Laughing Guide to Well-Being: Using Humor and Science to Become Happier and Healthier*.

**Dr. Ora Prilleltensky**

Clinical Assistant Professor
(Retired)

Department of Educational and
Psychological Studies
University of Miami

Dr. Ora Prilleltensky obtained her doctorate in Counseling Psychology from the University of Toronto. She is the former director of the major in Human and Social Development at the University of Miami and has taught various graduate and undergraduate courses. Ora has worked in a variety of clinical settings, including a child guidance clinic, a university counseling center and a rehabilitation hospital. Her research interests include Disability Studies and the promotion of well-being. She is the author of *Motherhood and Disability: Children and Choices* (Palgrave, 2004) and the co-author of *Promoting Well-being: Linking Personal, Organizational and Community change* (2006, John Wiley & Sons). She is co-author of the forthcoming book *The Laughing Guide to Change* with Isaac Prilleltensky. Ora is part of a research team developing online assessments and interventions to promote health and well-being (www.funforwellness.com). Ora currently serves on Miami-Dade County's Commission on Disability Issues. She is also on the board of Research and Reform for Children in Court.

**Lynnette Rasmussen, OTRL**

Occupational Therapist
PMA-Certified Pilates Trainer
Master Biocored Trainer
Department of Neurosurgery
Brachial Plexus Program
Ann Arbor, Michigan

Lynnette Rasmussen has worked in occupational therapy for over 39 years in a wide range of settings from pediatrics through adults. She has worked closely with an FSHD patient over the past several years and gave a talk at a Michigan FSH Society member meeting on techniques to identify and strengthen muscles that had been "lost". For the past 10 years her specialty has been working with brachial plexus palsy and she has published research, written book chapters and traveled throughout the world speaking on this subject. She became a national certified Pilates instructor and certified in suspension training to add to her movement expertise and offers many adaptations to achieve maximum movement. Lynnette has worked at the University of Michigan for the past 25 years in a variety of specialties and recently opened her own Pilates studio in the Ann Arbor area.

WESTIN COPLEY PLACE - THIRD FLOOR

