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To the Editors:

Rasmussen encephalitis (RE) was first described in 1958 by Theodore Rasmussen and colleagues at the Montreal Neurological Institute. RE is a very rare neuro-inflammatory disease characterized by intractable seizures and progressive unilateral neurological deficits. For most diagnosed cases, resection or disconnection of the affected cerebral hemisphere is the only effective treatment. The extreme rarity of the disease has hampered efforts to understand the cause of RE and to develop alternative non-surgical treatments. Usually only one or two RE cases may been seen annually at a pediatric epilepsy surgery center, thus it may take many years to accrue enough surgical specimens for research studies, especially those involving modern molecular techniques.

In 2011, The RE Children's Project (www.REChildrens.org), a non-profit organization founded to increase awareness of the disease and support research focused on finding a cure, brought together investigators from around the world to launch the RE Children's Research Consortium and discuss ways to accelerate the pace of RE research. With the support of the RE Children's Project, Johns Hopkins and UCLA launched an international Tissue Transfer Program and data bank to speed up the pace of RE research. The goal of the Tissue Transfer Program is to collect RE surgical specimens from epilepsy centers around the world and make biological samples and clinical data available for RE research. Between 2011 and 2012 the program was initiated with coordination managed at Johns Hopkins and in 2013 the role was transferred to UCLA. A central repository for the collected samples was established within the Rare Epilepsies and Brain Disease Tissue Bank in the Department of Neurosurgery at UCLA

(http://neurosurgery.ucla.edu/rare-epilepsies-tissue-bank). Excess material from a

planned epilepsy surgery that would otherwise be discarded, per institutional guidelines, would be collected for this purpose. All logistics would be handled by the Rare Epilepsies and Brain Disease Tissue Bank Coordinator at UCLA, who would liaise with donor institutions to facilitate the transfer of surgical specimens at no cost to the participating institution. IRB approval was obtained to collect surgical specimens from outside institutions, and to distribute material to other centers with institutionally approved research studies.

Since the inception of the Tissue Transfer Program, RE specimens have been collected from 33 surgeries at 19 epilepsy centers in six countries (Figure 1). Stored specimens include both fixed and frozen brain tissue, cerebrospinal fluid, whole blood, plasma, purified peripheral blood mononuclear cells and brain-infiltrating lymphocytes.

With increased awareness of this program, we hope that the pace of RE research will be accelerated. Epilepsy surgery centers around the world are invited to contribute samples and participate in this international effort to cure RE. Applications to access the RE repository should be directed to the Rare Epilepsies and Brain Disease Tissue Bank Coordinator at UCLA (http://neurosurgery.ucla.edu/rare-epilepsies-tissue-bank-contact-us). The Scientific Advisory Board of the RE Children's Project will review applications for research studies to ensure a fair and rigorous assessment of the proposed work.

In addition to RE, the Rare Epilepsies and Brain Disease Tissue bank is actively collecting specimens from other rare or uncommon pediatric epilepsy surgery cases including Hemimegalencephaly (HME), Focal Cortical Dysplasia (FCD), Tuberous Sclerosis (TSC). For more information visit http://neurosurgery.ucla.edu/rare-epilepsies-tissue-bank

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Ethical Publication Statement

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

Disclosure

Gary Mathern, MD, serves on the Editorial Board and ILAE Executive Committee for Epilepsia

William D. Gaillard, MD and Adam L. Hartman, MD serve on the Editorial Board for Epilepsia

The remaining authors have no conflicts of interest.

Carol A. Kruse, PhD[†, 1, 2]
CKruse@mednet.ucla.edu

Carlos A. Pardo, MD[3]
cpardov1@jhmi.edu

Adam L. Hartman, MD[3]
ahartma2@jhmi.edu

George Jallo, MD[3]
gjallo1@jhmi.edu

Eileen P. G. Vining, MD[3]
evining@jhmi.edu

Joe Voros, MPH[4]
joevoros@gmail.com

William D. Gaillard, MD[5, 6]
wgaillar@cnmc.org

Judy Liu, MD, PhD[5, 6]
JLiu@childrensnational.org

Chima Oluigbo, MD[5, 6]
coluigbo@childrensnational.org

Stephen Malone, FRACP[7]
stephen.malone@optusnet.com.au

Andrew F. Bleasel, MD[8, 9]
ableasel@usyd.edu.au

Mark Dexter, MBBS, FRACS[9]
mdexter@bigpond.net.au

Alex Micati, MPH[10]
alex.micati@health.nsw.gov.au

Tonicarlo Rodrigues Velasco, MD, PhD[11, 12]
tvelasco@fmrp.usp.br

Helio R. Machado, MD, PhD[11, 12]
hrmachad@gmail.com

Anthony M. Martino, MD[13]
amartino@health.southalabama.edu

Adam Huang, MD[13]
adamhuang3@gmail.com

B. Matt Wheatley, MD, PhD[14]
matt.wheatley@albertahealthservices.ca

Gerald A. Grant, MD[15, 16]
ggrant2@stanford.edu

Tiziana Granata, MD[17]
Tiziana.Granata@istituto-besta.it

Elena Freri, MD[17]
elena.freri@istituto-besta.it

Rita Garbelli, PhD[17]
garbelli.r@istituto-besta.it

Sookyong Koh, MD, PhD[18]
sookyong.koh@emory.edu

Douglas R. Nordli, Jr., MD[19, 20]
dnordli@luriechildrens.org

Alexandre Rainha Campos, MD[21]
rainha.campos@chln.min-saude.pt

Brent O'Neill, MD[22]
Brent.O'Neill@childrenscolorado.org

Michael H. Handler, MD[22, 23]
Michael.Handler@ChildrensColorado.org

Kevin E. Chapman, MD[22]
Kevin.Chapman@childrenscolorado.org

Angus A. Wilfong, MD[24, 25]
aawilfon@texaschildrens.org

Daniel J. Curry, MD[24, 25]
djcurry@bcm.edu

Amanda Yaun, MD[26]
Amanda-Yaun@ouhsc.edu

Joseph R. Madsen, MD[27, 28]
joseph.madsen@childrens.harvard.edu

Matthew D. Smyth, MD[29]
smythm@wudosis.wustl.edu

Deanna Mercer[29]
mercerd@wudosis.wustl.edu

William Bingaman, MD[30]
bingamb@ccf.org

A. Simon Harvey, MD[31]
simon.harvey@rch.org.au

Richard J. Leventer, MBBS, BMedSci, PhD, FRACP[31, 32, 33]
richard.leventer@rch.org.au

Paul J. Lockhart, PhD[32, 33]
paul.lockhart@mcri.edu.au

Greta Gillies, M. Sci[32]
greta.gillies@mcri.edu.au

Kate Pope[32]
kate.pope@mcri.edu.au

Cole A. Giller, MD, PhD, MBA, FACS[34]
cgiller@gru.edu

Yong D. Park, MD[34]
YPARK@gru.edu

Amyn M. Rojiani, MD, PhD, FACPE[34]
arojiani@gru.edu

Suash J. Sharma, MD[34]
susharma@gru.edu

Patrick Jenkins, PA-C[34]
pajenkin@gru.edu

Spencer Tung[1]
stung@mednet.ucla.edu

My N. Huynh[1]
MHuynh@mednet.ucla.edu

Thabiso W. Chirwa[1]
tchirwa@mednet.ucla.edu

Carlos Cepeda, PhD[1]
ccepeda@mednet.ucla.edu

Michael S. Levine, PhD[1, 2]
mlevine@mednet.ucla.edu
Julia W. Chang, PhD[1]
JWChang@mednet.ucla.edu

Geoffrey C. Owens, PhD[1]
GeoffreyOwens@mednet.ucla.edu

Harry V. Vinters, MD[1]
hvinters@mednet.ucla.edu

Gary W. Mathern, MD[1, 2]
gmathern@ucla.edu
(Corresponding Author)

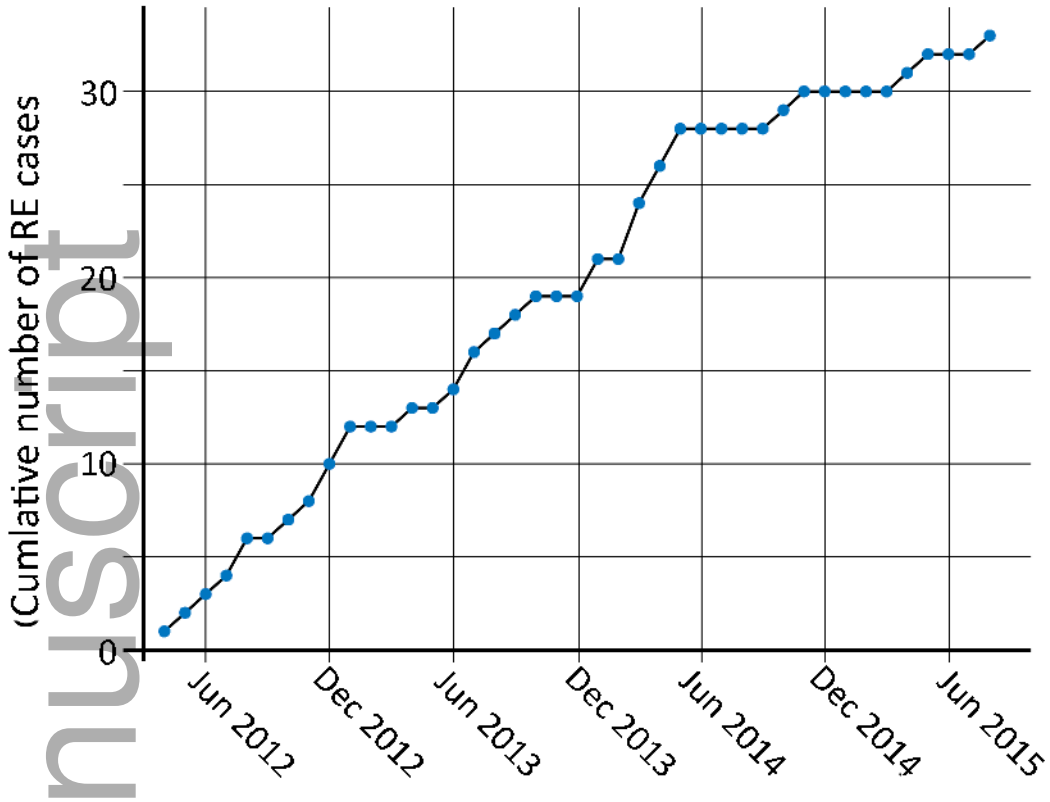
[1]David Geffen School of Medicine at UCLA, Los Angeles, CA, USA
[2]Brain Research Institute, UCLA, Los Angeles, CA, USA
[3]Johns Hopkins University School of Medicine, Baltimore, MD, USA
[4]Public Health Management, Los Angeles, CA, USA
[5]Children's National Health System, Washington, DC, USA
[6]George Washington University, Washington DC, USA
[7]Lady Cilento Children's Hospital, Brisbane, Queensland, Australia

[8]Westmead Hospital, Westmead, New South Wales, Australia
[9]The Children's Hospital at Westmead, Westmead, New South Wales, Australia
[10]The Sydney Children's Hospitals Network, Sydney, New South Wales, Australia
[11]Hospital das Clínicas de Ribeirão Preto, Ribeirão Preto, São Paulo, Brazil
[12]University of São Paulo, Ribeirão Preto, São Paulo, Brazil
[13]University of South Alabama, Mobile, AL, USA
[14]University of Alberta, Edmonton, Alberta, Canada
[15]Stanford University School of Medicine, Stanford, CA, USA
[16]Lucile Packard Children's Hospital, Stanford, CA, USA
[17]Fondazione I.R.C.C.S Istituto Neurologico Carlo Besta, Milano, Lombardia, Italy
[18]Emory+Children's Pediatric Research Center, Atlanta, GA, USA
[19]Children's Memorial Hospital, Chicago, IL, USA

[20]Ann and Robert H Lurie Children's Hospital of Chicago, Chicago, IL, USA
[21]Hospital de Santa Maria, Lisbon, Portugal
[22]University of Colorado Anschutz Medical Campus, Aurora, CO, USA
[23]The Children's Hospital, Aurora, CO, USA
[24]Texas Children's Hospital, Houston, TX, USA
[25]Baylor College of Medicine, Houston, TX, USA
[26]University of Oklahoma College of Medicine, Oklahoma City, OK, USA
[27]Boston Children's Hospital, Boston, MA, USA
[28]Harvard Medical School, Boston, MA, USA
[29]Washington University School of Medicine, St. Louis, MO, USA
[30]Cleveland Clinic, Cleveland, OH, USA
[31]The Royal Children's Hospital Melbourne, Parkville, Victoria, Australia
[32]Bruce Lefroy Centre for Genetic Health Research, Murdoch Children's Research Institute, Parkville, Victoria, Australia
[33]University of Melbourne, Melbourne, Victoria, Australia
[34]Medical College of Georgia at Augusta University, Augusta, GA, USA

Figure Legend:

Figure 1: Rasmussen Encephalitis tissue acquisition timeline June 2012 - June 2015



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