



PATIENT ALLIANCE FOR NEUROENDOCRINEIMMUNE DISORDERS
ORGANIZATION FOR RESEARCH AND ADVOCACY • 501 c 3 • ID # 550795076
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April 7, 2009

URGENT MATTER

The Honorable Bev Perdue
Governor of North Carolina
20301 Mail Service Center
Raleigh, NC 27699-0301
Fax: (919)-733-2120

Ref: **Ryan Michael Baldwin, Black Mountain, Buncombe County, NC.**

Dear Governor Perdue:

We are writing to you in reference to the situation of the Baldwin family and, more specifically, of Ryan Michael Baldwin, a young child, from Black Mountain, Buncombe County, North Carolina.

Ryan is medically disabled and has a diagnosis of chronic fatigue syndrome (CFS)(2004), severe autonomic dysfunction (2005), a progressive heart conduction system block (LBBB) with right axis deviation (2008), and mitochondrial disease (2008). He has been to Johns Hopkins (2004), the Mayo Clinic (2005), the Cleveland Clinic (2006), and was being referred to UNC Chapel Hill for mitochondrial disease (2008) when the Buncombe County NC Department of Social Services (DSS) interfered with all his medical care and, upon an anonymous physician referral, decided to remove Ryan from his home and place him in foster care; the Buncombe County DSS also took his power wheelchair, which he used daily to conserve energy.

Despite these serious confirmed medical diagnoses and wonderful care from his parents, Lisa and Rodney Baldwin, the Buncombe County DSS has charged his parents with child abuse under the Factitious Disorder by Proxy (FDP) (formerly known as Munchausen Disorder by Proxy) under the North Carolina statutes. It seems that in this particular case this statute was used due to a lack of understanding among many authorities as to the serious nature of CFS and current objective medical research on the illness. Children afflicted with CFS are quite ill. They require ongoing medical treatment and supportive assistance from their families.

Child abuse is a serious charge to be levied against any family or individual, specially under FDP, and we are cognizant of the mission and great responsibility that Ms. Amanda Stone of

DSS has in order to ensure the safety of children in Buncombe County.

However, we are also cognizant of the serious fact that the Buncombe County DSS may not have access to the scientific body of medical knowledge that is involved in the overall diagnosis of an individual suffering with chronic fatigue syndrome (CFS), also known as chronic fatigue immune-dysfunction syndrome, CFIDS, and in Europe and other countries, as myalgic encephalomyelitis or encephalopathy (ME). To our knowledge there is no medical personnel within Buncombe County Department of Social Services who is an expert in the neuroendocrine-immune disorders field.

We believe that no formal legal actions have ever been taken against parents with children afflicted with CFS, erroneously diagnosed as having Factitious Disorder by Proxy (FDP). The reasons being that when the child is removed from the parent (s) the children with CFS/ME remains ill, while the child suffering from FDP recovers. Because so many authorities and even many doctors are so poorly informed about CFS, such children are placed at considerable medical risk when removed from their families and denied the treatment and assistance they require. Recently there was such a case in England in which the CFS patient died.

CFS or ME is a complex and potentially extremely disabling illness that only recently has begun to receive more funding for research and attention towards medical care and potential treatments. The Center for Disease Control and Prevention (CDC) estimates that 1 to 4 million Americans are stricken with this illness, which has many subsets and affects children, teenagers, young adults, adults, and the elderly.

The basis of the charges brought against the Baldwin family is not consistent with the medical diagnosis and medical care that, over the years, the family has diligently pursued for their son Ryan. The overzealous attempt by the Buncombe County DSS is misdirected. Its resources should be used to ensure that the family has the environment needed to facilitate medical access and home schooling for Ryan. Removing him from his home and placing this child in foster care is not in the best interest of the child or his family.

Therefore, we urge you:

- To investigate and take action in this matter to ensure that the Baldwin family is reunited with Ryan as soon as possible. Please assist the Baldwin family before their child is placed a greater risk, and before medical and emotional harm is afflicted upon their child.
- To establish steps within your office and state by instituting a medical provider training through your State Department of Health so that in the future parents and their children stricken with CFS/ME will not have to go through this hellish situation. P.A.N.D.O.R.A. and the organizations/individuals listed in this letter, have resources that we can provide to implement this training in place. The resources are CFS/ME researchers, physicians, and other medical experts who can provide specific CME and CEU training through the North Carolina Area Health Educations Centers Program (AHEC) to physicians, mental health counselors, registered nurses & physician assistants and other allied medical providers, as well as social services providers, and teachers. An awareness of this

illness, as well as other neuroendocrineimmune disorders (NEIDs) such as fibromyalgia (FM), Gulf War syndrome (GWS), multiple chemical sensitivities (MCS) or environmental illness (EI), and chronic Lyme disease (CLD), should be in place. We believe that this important educational initiative could have prevented the Baldwin Family ordeal. Once this training is implemented, we believe it will prevent other families with children and young adults diagnosed with CFS/ME having to face the same ordeal.

We have also spoken with Mr. Jerry Rice, a long-term resident of Buncombe County, with strong ties to the community, and who as an advocate and community activist has embraced the Baldwin family's plight. Mr. Rice has been helping the family for more than 5 years on issues pertinent to Ryan's care. Without Mr. Rice's assistance, as we were told by his family, they would be without any hope.

I would like to discuss this issue with a representative from your office. An unconfirmed court hearing has been scheduled for the week of April 6, 2009. (Wednesday or Thursday) Therefore this is a matter of great urgency!

The undersigned below are the organizations that respectfully urge you to take action on our request. I can be contacted at 954-783-6771 or on my cell phone at 954-629-0976.

Sincerely yours,

Marly C. Silverman

Marly C. Silverman

Founder

P.A.N.D.O.R.A.

cc:

Mr. Lanier M. Cansler, NC Secretary of Health

Mr. Paul Waddle, DHHS Division of Social Services

Ms. Amanda Stone, Buncombe County, Director/Ass.County Manager

Ms. Susan Fisher, NC House Representative

Mr. Bruce Goforth, NC House Representative

Ms. Jane Whilden, NC House Representative

Mr. Martin Nesbitt, NC House Representative

Mr. Heath Shuler, U.S. House of Representatives

Senator Tom Apodaca, NC State Senator

Senator Kay Hagan, U.S. Senate

Commissioner David Gantt, Chairman, Buncombe County

Commissioner David Stanley, Vice-Chairman, Buncombe County

Commissioner Kay Ray Bailey, Buncombe County

Commissioner Holly Jones, Buncombe County

Commissioner Carol Peterson, Buncombe County

Mr. Grier Hurley, Ashe County Attorney

Ms Deborah Weaver, Ashe County DSS Director

**Organizations Signatures that have jointly signed on this letter to Governor
(electronic signatures are confirmed by e-mail)**

Sandi Lanford, President
The Lanford Foundation - LifeLyme - <http://www.lifelyme.org/>

Daniel Moricoli, Founder
CFSknowledgecenter.com- www.CFSknowledgecenter.com

Pat Fero, Executive Director
The Wisconsin CFS/ME Association - <http://www.wicfs-me.org/>

Yvonne Keeny, Founder & Executive Director
Fibromyalgia Coalition International- <http://www.fibrocoalition.org/>

, Manager
The Co-Cure ME/CFS and Fibromyalgia Information Exchange Project - www.co-cure.org

Nancy M. Henson, 25-yr Veteran Patient, Advocate and Editor of the Charlotte Area
ME/CFS/FM Support Group E-Newsletter, Charlotte, NC

Janet Wildeboer - West Michigan CFIDS Organization Inc

Sparrow Ivy, Carrie Nelson, Karen Clinton
Reaching Out Co-Founders (www.reaching-out.info)

Carrie Nelson, Newsletter Editor & Advocate - Reaching Out
Topeka, Kansas

Rich Carson, Founder - Pro-Health.com <http://www.prohealth.com/aboutus/index.cfm>

Rik Carlson, President - The Vermont CFIDS Association
"Turning the Tides of Modern Medicine is No Small Task."
<http://www.vtcfids.org>

, Founder, Phoenix Rising - <http://phoenix-cfs.org/PhoenixRisingsubscribe.htm>

, President & Founder -H.O.P.E. - Helping Our Pain and Exhaustion, Inc.
<http://www.hffcf.org/>

Jean Harrison, President, M.A.M.E. - Mothers Against Myalgic Encephalomyelitis, Inc.

Peggy Walk, President - The New Jersey CFS Association- <http://njcfsa.org/>

Carvi Shamsid-Deen, Support Group Leader, CFS/FM Support Group of DFW
<http://www.dfwcfids.org>

Carol Sieverling, Treasurer, CFS/FM Support Group of DFW Eules, TX

, President The CFIDS-ME Information Group
<http://www.cfids-me.org/>

Claudia Wentland, President, CFS/FM Organization of Georgia support@cfog.us
Atlanta, GA

Karen Campbell, Founder - CFS-Facts.org www.cfs-facts.org

Carole Howard, Executive Director - Chronic Fatigue Syndrome, Fibromyalgia and Chemical
Sensitivity Coalition of Chicago - CFCCC <http://www.cfccc.net/>

Lois Ventura, Steven Du Pre, Co-Founders - National Alliance for Myalgic
Encephalomyelitis
www.name-us.org

INDIVIDUALS

Jerry Rice, Community Advocate, Buncombe County, NC
Kenneth Friedman, PhD, Associate Professor, University of New Jersey Medical School.
Herbert Hyman, MD - CFS Specialist & Family Physician, West Palm Beach, Florida
Peter Ventura, Caregiver to M.E. patient, 11 years, Western Pennsylvania
Linda Barossi - Auburn, California
John Herd CFS/ME Advocate & Blogger, Santa Barbara, CA
Deborah Schlindwein Schmidt , Athens, Georgia
Rosemary Underhill, MB BS. CFS/ME Researcher, NJ
Mike Munoz 2007 CFS Advocate Extraordinaire & former Pres., The CFIDS/FM Rocky
Mountain Association.
Laura Sutherland, Dallas, TX
Jannell Burchard Lodi, Wisconsin
Michelle Roy, CFS/ME Advocate Bedford, TX
Kellyann Wargo, Dallas, Texas
Amy Rotenberg, Thornhill, Ontario Canada
Nicola Huntley, Norwalk CT
Anita K. Patton CFS/ME Patient of 23 years, Reno, Nevada
Courtney Alexander, Robert Miller, Annandale, VA 22003

4/08/09 - Final (amended 05/01/09)