# The Cerebral Palsy Group Newsletter

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Cerebral Palsy Group of 5

Health Care Reform

7 Author: John Quinn

**Current Issues & News** 

Revolution

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### A New Partnership: The CP Group & CPIRF

The Cerebral Palsy peers. The CP Group can International Research Foundation has asked The CP Group to support their efforts to increase the health and wellbeing of adults with CP. The Foundation recognizes that adults with CP have complications that have been under-recognized, undocumented, and undertreated. Most adults with CP experience earlier onset of joint pain and arthritic complications than the general public. There are no clinical programs for adults with CP and medical education has not to date provided a forum for dealing with the needs of this community. The CP Group can play a major role in changing these conditions. Medical

researchers have begun to

coordination and losses in

ration of balance and

motor control that many adults with CP experience years before

their nondisabled

document the pain, deterio-

support this research by continuing to spotlight the Difficulties facing adults at our conferences and on the listsery.

Additionally, the growth of the CP Group provides researchers with people who can participate in research undertaken at universities and hospitals. The Group will also step up its advocacy efforts by contacting elected representatives and asking them to support more funding for CP related issues.

The Foundation has generously awarded The CP Group a grant to support our efforts on behalf of adults with CP and to help offset the financial deficits associated with our conferences. Visit the

Foundation's web site at www.CPIRF.ORG



# 2010 CP Group Conferences

The CP Group is holding two Conferences in 2010

# West Coast Conference

Co-sponsored by the Area Board VII, Office of the State Council on Developmental Disabilities.

June 25th - June 28th, 2010 San Jose, California

Location: Doubletree Hotel San Jose, California

Date: June 25th - June 28th

Conference Fee: \$290 for the full conference or \$140 for a conference day



Dr. Mindy Aisen is a co-editor of a the publication on the medical issues confronting adults. She will be at the CP Conference in San Jose California on June 25th-28th to discuss how new technologies may help prevent or treat the effects of accelerated aging as well as other subjects in the publication including complementary and alternative medicine, osteoporosis, pain management, baclofen, and scoliosis. Dr. Aisen's presentation This will betake place on Friday, June 25, 2010 from 3:00 pm – 5:00 pm

# East Coast Conference

SAVE THE DATE October 15th –18th, 2010 Doubletree Hotel Arlington, Virginia





#### **International News**

In January 2010, the CP Group hosted a Delegation from Ghana Africa who represented their Country's National Council on Persons with Disability (NCPD). Ghana's President Atta Mills as part of his campaign promised established the NCPD in April 2009. The Council is charged with educating and modifying Ghana's Society so that individuals with disabilities are mainstreamed and have the same equality and opportunities as people without disabilities.

Andrew Okaikoi, NCPD Chairman, an individual with a disability lead the Delegation that met with leaders of organizations that serve and advocate for individuals with disabilities in the United States. Members of the Delegation learned about the disability movement in the United State by Judith Heumann, a pioneer of the independent living movement in this country, and Bob Williams who was appointed by President Clinton to as the chief disability policy-maker in Clinton's administration.

Andrew Imparato, President & CEO, of American Association of People with Disabilities (AAPD) emphasized the need for Ghana to empower people with disabilities and family to be the advocates for creating an accessible society. Jenifer Simpson, AAPD Sr. Director Telecommunications & Technology Policy, spoke about being a parent of a son with cerebral palsy and the significant role advocates play in creating laws and polices that result in a more accessible society.



**Ghana Delegation at AAPD** 



David Morrissey, Executive Director of the United States International Council on Disabilities, discussed the correlation between human rights and the rights of people with disabilities. The purpose of the human right movement is to assure that all human beings have the same rights and freedoms to live their lives independently. People with disabilities, like all citizens around the world, should be able to give their views on political, social, and civil rights without fear of harassment or prejudice. There are great benefits when international disabilities organizations collaborate with international human rights organizations resulting greater strength in all our efforts.

The Ghana Delegation also met with Richard A. Simms the Executive Director of the Independent Living Center (ILC) in Washington and the Center's staff. They learned about how ILCs throughout the United States provide advocacy and services to advance the independence of people with disabilities in their own communities.

The Ghana Delegation visited the National Rehabilitation Hospital (NRH) and received a tour of the facilities. NHR specializes in treating persons with physical disabilities caused by spinal cord and head injuries, stroke, arthritis, amputation, multiple sclerosis, post-polio syndrome, and other neurological and orthopedic conditions, including CP.

The Ghana Delegation was very impressed with the two days that they spent meeting leaders of the disability movement and touring innovated programs that advance the independence of people with disabilities. \_This experience allowed them to gain more knowledge to share back in Ghana as the NCPD works toward giving true equality to their citizens with disabilities.

There was agreement among the representatives from the organizations that met with the Ghana Delegation that they will continue to provide support and assistance to the NCPD as it works to increase the rights of people with disabilities.

















## The CP Group 1st International Affiliate

#### BRIEF HISTORY OF THE CEREBRAL PALSY GROUP GHANA (CPGG)

The Cerebral Palsy Group of Ghana (CPGG) was established last year upon the directives from the Chairman of National Council for Persons with Disability (NCPD) Ghana.

Chairman Andrew Okaikoi after his Swearing in as the Chairman of the NPCD by H.E John Dramani Mahama Vice President of the Republic of Ghana on the 7<sup>th</sup> of April 2009, has given priority to identify the Various Disability Groups that are not officially formed and functioning in the Country. In view of this he charged Mr Wilson Agbesi Yao of the Research Division of the NCPD to research and see how best the Council can get in contact with all the Disability Groups around the World, so that the Council could learn from their rich experiences as much as their activities are concern.

In the course of his research Mr. Agbesi Yao liaised with Molly Kennedy of the Cerebral Palsy Group (US) who has really been a great blessing to the CPGG. Molly Kennedy has always been in contact with the NCPD and the newly established CPGG, providing the Group with a lot of advice and vital information towards the smooth running of the newly born CPGG.

Additionally, she has contributed significantly by coordinating a meeting for the NCPD and the Leaders of the Disability Movement in the United State of America, which was held in Washington DC in January this year. The purpose of the meeting was to give the NCPD the opportunity to create a formal working relation with members Disability Movement in the United States .

The CPGG is currently managed by an Interim Board of Trustees, comprised of the following people,

i. Mr Andrew Okaikoi Chairman (NCPD)

ii. Mr Raphael Kwasi Yaadar Physiotherapist (Korle Bu Hospital)

iii. Mr Wilson Agbesi Yao Research Officer (NCPD)

iv. Miss Sandra Casamar Physiotherapist (Korle Bu Hospital)

v. Miss Regina Amanorbea Dodoo CEO (GOFAS)

Additionally, Mr Wilson Agbesi Yao currently serves as the Project Coordinator for The Cerebral Palsy (US) and The Cerebral Palsy (Ghana) Partnership. The CPGG will officially be inaugurated in May,2010 and would immediately embark on a year long awareness creation Campaign in the entire Country as a way of creating awareness on Cerebral Palsy and its ramifications in Ghana.

It is our hope and prayer that the CP (US), other Disability Organization and donor Agencies in the United States will assist the CPGG in fulfilling its outlined Programs and Activities. Finally, the CPGG would like to extend its greatest appreciation to the following people and Organizations for their hard work and contribution towards the successful establishment of the Organization. Mr Andrew Okaikoi of the NCPD, Madam Molly Kennedy of the CP (US), Mr Wilson Agbesi Yao of the NCPD, The National Council for Persons with Disability (NCPD) Ghana, The Physiotherapy Department, Korle Bu Teaching Hospital Accra Ghana and the Cerebral Palsy Group of America.

Long Live CPGG, Long Live CP Group(US).

# Topic of the Day

# Health Care Reform Benefits for People with Disabilities

Here are the good things in the Health Care Reform Bill passed by Congress for people with disabilities and access health care service. Prohibits private health insurance exclusions for pre-existing conditions; eliminates annual and lifetime caps in private insurance policies; restricts the consideration of health status in setting premiums and expanded Medicaid to cover individuals with incomes up to 133 percent of the federal poverty line (approximately \$29,000 per year for a family of four).

**Benefits** 

Ensures that minimum covered benefits include products and services that enable people with disabilities to maintain and improve function, such as rehabilitation and habilitation services and devices.

Access to Quality Care: Improves training of physicians, dentists, and allied health professionals on how to treat persons with disabilities. Requires the Centers for Medicare and Medicaid Services to collect data on beneficiaries with disabilities access to primary care services and the level to which primary care service providers have been trained on disability issues. Ensure prevention programs include a focus on individuals with disabilities.

Long Term Services and Supports: Increase the Federal share of Medicaid, known as the Federal Medical Assistance Percentage (or FMAP), for home and community based services (HCBS) and during periods of economic downturn. Allowing states to offer additional services under the 1915(i) Medicaid HCBS Waivers State Plan Option; provides spousal impoverishment protections for HCBS Beneficiaries; strengthen long-term services and supports through a two pronged approach: Taking pressure off of the Medicaid program: The Community Living Assistance Services and Supports (CLASS) Act would create a national long term services insurance program which assists eligible individuals and their families to meet long term needs with a cash benefit and without forcing them into poverty to receive Medicaid benefits.

Improving the Medicaid program: The Community First Choice Option would help to eliminate the institutional bias by encouraging states to cover personal attendant services under the state's optional service plan instead of through the waiver system by offering a 6% increase in the federal share of Medicaid for these services.

#### **Author! Author!**

John Quinn was born with cerebral palsy. He also had a dream to serve his country. Keeping his CP a secret, he was able to join

the United States Navy and retire as a Senior Chief Petty Officer after a highly successful twenty-year career. His memoir, Someone Like Me - An Unlikely Story of Challenge and Triumph Over Cerebral Palsy, is now available from History Publishing Company. You can order a copy of the book online at Amazon. Borders Books, or Barnes and Noble sites.

For more information about Someone Like Me, and

how to obtain a personalized autographed copy, check out John's website at <a href="https://www.johnwquinn.com">www.johnwquinn.com</a>

John will be speaking about his journey and how he came to write the book at the West Coast Cerebral Palsy Conference in San Jose, California June 25th-28th 2010

#### Sail Away with the CP Group

The CP Group and Dateable are going to take over the Royal Caribbean International's newest, largest and most innovative ship

#### Allure of the Seas.

Day	Ports of Call	Plan to set sail January 9, 2011 to these fun and ex-
Sun	Fort Lauderdale, Florida	otic locations:
Mon	Nassau, Bahamas	
Tue	At Sea	Pricing:
Wed	St. Thomas, Virgin Islands	Cat L Inside stateroom \$ 830.00 per person double occupancy plus taxes
Thu	St. Maarten, Netherlands Antilles	and port fees
Fri	<u>At Sea</u>	Cat D7 Veranda stateroom \$1090.00 per person double occupancy plus
Sat	At Sea	taxes and port fees
Sun	Fort Lauderdale, Florida	Cat C1 Central Park View stateroom \$1140.00 per person double occupancy plus taxes and port fees

All cabins are per person double occupancy. The taxes for the cruise are the same for all categories and are as follows: \$265.28 per person. We need names and 500.00 per cabin to reserve the accessible staterooms. Initial deposits, to keep the guarantee of staterooms we blocked is \$1500.00, which is due by March 14, 2010. Full deposits are due (for non accessible staterooms) August 1, 2010 and final payment is due by October 15, 2010. Other cabin categories are available and may be booked, the prices will be determined at the time of booking. The category's reserved have accessible staterooms in their particular category, but that does not guarantee one will be available at the time of booking, as there are limited number of cabins in certain categories.

For more information contact Avant Garde Travel: Al Wyllie362 Ashland Ave. Wyoming, De 19934

# Current News & Issues For Adults with Cerebral Palsy

- ⇒ Proposal 2011 Federal Budget & Its Impact on People with Disability <a href="http://www.aahd.us/site/static/pdfs/policy/Disabilitybudget.pdf">http://www.aahd.us/site/static/pdfs/policy/Disabilitybudget.pdf</a>
- ⇒ Report from the National Council on Disability "The Current State of Health Care for People with Disabilities

http://www.ncd.gov/newsroom/publications/2009/HealthCare/HealthCare.html

- ⇒ BREAST EXAMINE SURVEY: The American Association on Health and Disability (AAHD) has received a grant from Susan G. Komen for the Cureâ AAHD has received a Komen Race for the Cureâ Community-Based Grant for 2009-2010 to implement a comprehensive education and empowerment intervention for women with disabilities who face physical, cultural, and linguistic barriers in receiving breast health care services at mammogram facilities in the greater Washington, D.C. area. There is a survey on the AAHD website that women with disabilities can complete on how accessible it is to get a mammogram. If you are a woman with a disability, please take a few minutes to complete the survey: http://www.surveymonkey.com/s/G77ZLF3
- ⇒ An article of about a woman with cerebral palsy talks about being pregnant and being a mom. http://www.ncpad.org/yourwrites/fact\_sheet.php?sheet=775



#### It's Time. Make Yourself Count. Census 2010

The census influences the distribution of more than \$400 billion every year in federal funds for programs in education, health care, community services, economic development and more. In fiscal year 2007, the federal government used census information to guide the distribution of approximately \$15 billion in services specifically to people with disabilities. In addition, census data are used by state and local governments and private corporations to guide investments in transportation, restaurants, shopping centers and other types of economic development.

Make Sure you fill out the Census Form

# Be Part of the Revolution

The Cerebral Palsy (CP) Group is starting a revolution to improve the lives of adults with cerebral palsy and we want you to be a part of it!! The following are ways you can be part of the revolution:

- Individuals with cerebral palsy can register to be member of the CP.
- Attend one of the CP Conferences.
- Become involved in planning a CP Conference.
- Write an article for the Newsletter.
- Assist with securing funding for the CP Group.

To Register to be an associate of the CP Group visit the CP Website www.thecpgroup.org

Submit an Article, Story, Event, or other interesting tidbits please email them to the newsletter editor Molly Kennedy at kennedymolly@att.net.

# THE REVOLUTION BIGINS WITH

