



POST POLIO SYNDROME – a challenge of today

COPENHAGEN // AUG 31 – SEP 2 2011

Conference Summary

Frans Nollet

Chair Scientific Committee



POST POLIO SYNDROME – a challenge of today

COPENHAGEN // AUG 31 – SEP 2 2011

Great success

- 350 participants from 28 countries
 - (50% polio survivors, 50% health care providers)
- 21 sessions
 - 66 presentations, 33 posters
- Great venue, excellent organized by PTU





POST POLIO SYNDROME – a challenge of today

COPENHAGEN // AUG 31 – SEP 2 2011

Program

- High quality presentations covering many topics ranging from research to care and personal experiences
- High attendance and excellent informal atmosphere
- Valuable interactions '*between and across*', we need each other!



POST POLIO SYNDROME

– a challenge of today

COPENHAGEN // AUG 31 – SEP 2 2011

Some highlights

- Poliovirus eradication program, a huge and important effort to finish this successfully!
- *Importantly, WHO now has started to think about further care for those affected by polio*





POST POLIO SYNDROME

– a challenge of today

Diagnosis & assessment

COPENHAGEN // AUG 31 – SEP 2 2011

- PPS definition criteria have been established now for 10 years (March of Dimes 2001), but the application of investigational examinations (EMG, imaging, blood testing) is not unified.
- There is interest to discuss this further with the aim to agree on a diagnostic work up protocol.
- <http://www.marchofdimes.com/downloads/PostPolio.pdf>



POST POLIO SYNDROME

– a challenge of today

COPENHAGEN // AUG 31 – SEP 2 2011

Research

- Studies of different size are done in many places in Europe.
- There is interest to cooperate in research.
- Further agreement upon a set of common outcome measures needs to be achieved.
- The complementary value of qualitative and quantitative research is acknowledged, also illustrating that researchers and polio survivors need each other to achieve the best results.



POST POLIO SYNDROME

– a challenge of today

COPENHAGEN // AUG 31 – SEP 2 2011

Cause and treatment

- Further research to the cause of PPS, including viral genetic research, immunological factors, and treatment options based on these is on its way.
- A new international IVIG study is anticipated in the near future.



POST POLIO SYNDROME

– a challenge of today

COPENHAGEN // AUG 31 – SEP 2 2011

Rehabilitation therapies

- Interdisciplinary team work is paramount, involving the polio survivor as a team member.
- Mental support in the process of change is important.
- Components of therapy need further study to proof their effectiveness such as exercise.
- Orthotic developments may be beneficial for many and their availability needs to be improved.





POST POLIO SYNDROME

– a challenge of today

COPENHAGEN // AUG 31 – SEP 2 2011

Care in Europe

- The availability of Care in Europe is in many countries not sufficient! There is work to do.
- Evidence based treatment recommendations need to be agreed upon and published as *Standards of Care*.
- Preventive measures and implementation of preventive care programs should be an important goal as well.

What we achieve in Europe, not excluding other continents, may benefit later generations in endemic countries across the world.



POST POLIO SYNDROME

– a challenge of today

COPENHAGEN // AUG 31 – SEP 2 2011

Networking

- It has been agreed that EPU will be supported by a Medical Scientific Advisory Board to assure high standards of information on topics such as care recommendations.
- The Scientific Committee of this Conference will initiate this task.
- The EPU website will expand their informative activities and issue electronic newsletters.
- A network will be formed to accommodate communication between interested clinics in Europe including all relevant disciplines for clinical practice and research issues.



POST POLIO SYNDROME – a challenge of today

When you go home

- Feel strengthened by the experience that you are now part of a European group and that together we can achieve more.
- You all here are ambassadors for polio care!
- Report back to your organisations.

COPENHAGEN // AUG 31 – SEP 2 2011



POST POLIO SYNDROME – a challenge of today

COPENHAGEN // AUG 31 – SEP 2 2011

Next Conference

- Should we do it again in 2 years? And where?
- Will you come again and advice others to come?
- Please fill in your evaluation forms and suggestions for improvements are welcomed.

PowerPoints and Supplement of JRM will be displayed on the Conference website. The filming of the sessions in 14 days.



POST POLIO SYNDROME – a challenge of today

COPENHAGEN // AUG 31 – SEP 2 2011

Thanks to

- EPU board for initiating this meeting.
- PTU for organizing.
- Scientific Committee members for the content.
- All presenters.
- All participants.