

EUROPEAN POST POLIO NEWS

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European Polio Union



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MESSAGE FROM THE PRESIDENT OF THE EPU



A New Year, new challenges and fresh opportunities that's what 2012 offers us all. The EPU is no different, it faces many obstacles and challenges in uncertain times, in some ways it even reflects the differences and difficulties that affect the Eurozone and threaten the existence of not just the currency but the EU as an entity. However, EPU is different it represents more than just the EU countries and can call upon the expertise and knowledge of polio Survivors and medical Professionals all the way from the North Cape of Norway to the borders of Turkey and its southern neighbours.

This Newsletter represents one of the objectives spelt out in Copenhagen, but this is not a box ticking exercise where the Board can say how good it is, rather it is a demonstration of commitment to you, our members, and to polio Survivors all over Europe, not just the EU! It is here to give you news, keep you up to date with latest events and allow you a voice to express your opinions on matters affecting Polio Survivors and those with Post Polio Syndrome. Write in, contact details on front page and I will do my best to include as many as possible.

The Board has been listening to you and has made changes. For example members were concerned that minutes of Board meetings and Annual General Meetings were included and could be downloaded from the web site (www.europeanpolio.eu). They have been removed and in the future will only be distributed by email to full and associate members. However, to demonstrate and inform others of the work done by the EPU it is intended that this Newsletter will be on the web site. A further demonstration of the Board listening is that many concerns about the governance of the EPU were raised at the AGM, these will be addressed in detail at the 2012 AGM to be held, subject to confirmation, in the Czech Republic at the end of August or beginning of September. Full and associate Members will receive further details of these deliberations by email in the near future.

In the meantime I hope you enjoy this Newsletter and it is hoped that it will go out at least 3 if not 4 times a year. It is not my newsletter or that of the Board but YOUR Newsletter so if you have anything for the next edition send it in. All members are free to contact me or other Board members at any time; we are acutely aware that you are the members and we represent you and in doing so must serve your best interests. I realise one of those is for everything to be multi lingual – please just give us a little extra time on that one

John R McFarlane

EUROPEAN POLIO UNION JOINS EUROPEAN DISABILITY FEDERATION

One of the many objectives announced at the Annual General Meeting on 30 August 2011 in Copenhagen was the intention that the EPU should join the European Disability Federation / Le Forum Européen des Personnes Handicapées – www.edf-feph.org. Early in October an application was made and the EPU was admitted as an associate member. Full membership can only be obtained when we have more than 50% of EU countries represented.



On the 13 November EPU received a welcome message from Yannis VARDAKASTANIS, E.D.F President;-

“I have the honour to announce that the EDF Board of Directors meeting in Warsaw last October has approved the application of your organisation as Associate member of the European Disability Forum, following your request.

In the next few days your Secretariat will start receiving our mailings on EDF activities and campaigns and your organisation will be also listed on our web site.

I would like to thank you once again for the invaluable support that you are bringing to our organisation and to the European Disability movement as a whole.

Please do not hesitate to contact EDF’s office for any further information you may require.

Yours sincerely”

Since then the EPU Board have been in touch with the EDF Secretariat and are hoping to visit their offices in Brussels at the beginning of February 2012, as well as having an initial meeting with the relevant Directorate in the European Commission to discuss methods of funding and areas where it can avail of EU Commission assistance.

Note: **The European Disability Forum**

The European Disability Forum is an independent NGO that represents the interests of 80 million Europeans with disabilities. EDF is the only European platform run by persons with disabilities and their families. It is the front runner for disability rights. It is the voice of persons with disabilities in Europe.

POST POLIO SYNDROME – The Challenge for Today

Copenhagen 31 September – 2 October 2011



Chaired by Prof. Frans Nollet (pictured left), Univ. of Amsterdam, who received an award for his work in the treatment and research into PPS

Scope of the Conference

The primary aim of the conference was to bring patients, health care providers from different professions, and researchers together to find ways to improve care for Polio Survivors in Europe and to stimulate research in this area. The conference was initiated by the European Polio Union, the umbrella organisation of 19 Polio patient unions in 13 EU countries, and organized by the Danish Polio Society PTU. The program was decided by a joint committee of European researchers and EPU representatives.

The conference was attended by 330 participants from 25 countries from all continents. Half of them were patients, spouses and carers, and half health care providers and researchers. The program consisted of 21 sessions and included almost 70 lectures.

The conference atmosphere was excellent with high attendance of sessions. The opportunity to meet, exchange ideas and discuss between patients and professionals was highly appreciated and fruitful.

MAIN CONCLUSIONS

Research

- The most promising research area to the cause of Post Polio Syndrome focuses on the role of inflammatory factors that may be related to persistence of Polio virus fragments in the genome. Based on this, intravenous immunoglobulins may be beneficial to arrest or reduce the loss in strength and functional decline due to Post Polio Syndrome.
- A recent Cochrane review concluded that the evidence for both pharmacological and rehabilitation interventions are insufficient and guidelines are based on limited levels of evidence.
- Therefore, high quality research to the effectiveness of pharmacological and rehabilitation interventions are needed, including cost-effectiveness evaluations to facilitate implementation in health care systems.
- Research interest needs to increase. Although research is being conducted in this area, the number of intervention studies in progress is scarce. Trial registries mention only one randomized study of rehabilitation interventions including health-cost evaluation.
- Research is hampered by little research interest, based on the false notion that Post Polio Syndrome is irrelevant because Polio is a disease of the past, and, as for many orphan diseases, by funding barriers to execute pharmacological studies.
- The following specific priority topics for intervention studies were identified:
 - 1) Effectiveness of immunoglobulins needs to be confirmed. An international multi-centre study is in preparation.

- 2) Effectiveness of multidisciplinary rehabilitation and its components such as exercise and psychological interventions.
- 3) Symptom management, especially to reduce fatigue and pain.
- 4) Interventions to reduce the high rate of falls and subsequent injuries; studies should include the prevention of osteoporosis in underdeveloped limbs.
- 5) Prevention of secondary damage to the locomotory system in aging Polio Survivors due to long term abnormal overloading of limbs.
- 6) To warrant healthy aging and to reduce the negative influence of multi morbidity and life style factors such as overweight and inactivity.
- 7) The effectiveness of orthotic innovations.

Care

- Care should aim at societal participation at the highest functional level, and should be provided by interdisciplinary rehabilitation teams including the individual with Post Polio Syndrome as full team member.
- An inventory among 19 Polio unions in 13 European countries revealed a lack of interest and knowledge in many countries and few specialized clinics and poor access to help. Yet, it is estimated that around 700.000 EU inhabitants will suffer from Post Polio Syndrome.
- To improve care provision in the EU, standards of care should be formulated and published.
- Each EU country should have an expertise centre for Post Polio Syndrome to improve care at the national level.

Networking

- Post Polio Syndrome must be kept on the political agenda, as major health care issue in the EU, and is a major aim of the European Polio Union.
- EPU will be strengthened by establishing a medical advisory board.
- More national Polio patient organisations need to join the EPU and EPU may be instrumental in setting up patient organisations in European countries so far lacking such unions.
- A professional European network of health care professionals and researchers with interest and expertise on Post polio Syndrome to improve care and facilitate research will be established and facilitated by EPU.
- Priorities of the professional network are to establish diagnostic and therapeutic guidelines and to define a standard set of outcome measures for clinical research purposes.

Endemic countries

- The WHO considers initiatives to improve rehabilitation care, especially in developing countries for the millions of people growing up and living with the lasting impairments of Polio, to ensure that they can life full lives.
- The knowledge on Post Polio Syndrome in developed countries should be transferred to developing countries to seek ways to prevent Post Polio Syndrome and the secondary damage due to physical overloading and to set up care for Post Polio Syndrome that will also become a future issue in these countries.

Next Conference - The next conference will be held in 2 years, likely in Amsterdam.

THE MISSION FOR THE EPU

Post Polio Policy in the EU

Holger Kallehauge, retired High Court Judge & President of PTU (pictured right) gave this address to the conference during the closing session. (*PTU organised the conference and are members of EPU*)



The conference in Copenhagen has more than one goal. The primary goal is of course to share knowledge and information about the Post Polio Syndrome, and the diagnosis, the symptoms, treatment and how to live with and if possible how to overcome some of the symptoms. This is equally important for the health professionals as for the Polio Survivors.

My subject is however another and more general:

How shall we in The European Polio Union (EPU) enhance and work for:

- Research in Post Polio
- Adequate rehabilitation, training and treatment to all Polio Survivors
- Development aid to Polio Survivors in poor countries in the third world

How shall we make best use of the UN Convention of December 13th 2006 about the rights of persons with disabilities (CRPD) to forward the three above mentioned goals at a national, European and global level?

1. The UN Convention on the Rights of Persons with Disabilities

The UN Convention about our human and fundamental rights is a most useful instrument in all disability matters, also when it comes to health issues as the Post Polio Syndrome.

The convention does not deal directly with Polio Survivors or with Post Polio as we all know, but is a general set of legally binding rules dealing with all aspects of disability affairs. Therefore the convention is - as I shall try to demonstrate in my intervention - also both applicable and instrumental for us in our efforts to formulate an EU Polio policy if we read, understand and interpret the convention correctly.

As an opening I shall point to article 3 in the convention about general principles covering rules as respect for our human dignity, autonomy and freedom to make our own choices.

But also fundamental rights as

- non-discrimination
- full and effective inclusion in society
- equality of opportunities, and
- accessibility

Respect for these fundamental rights is now an universal obligation as it is also confirmed by the EU ratification of the convention as well as by a majority of the EU member states.

The purpose of the UN Convention is as it is stated in article 1 to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms for all persons with disabilities.

Without awareness-raising as prescribed in article 8 of the convention no Post Polio policy in the EU shall have any chance of being realized. Issue number one after having formulated such a policy is to spread the message and thus making it clear primarily to the EU decision makers, parliamentarians, ministers in the EU Council and members of the Commission what our goals are. Such a campaign has at the same time to be duplicated at the national level by EPU member organizations vis-a-vis the national ministers of health and other health authorities.

The convention articles number 25 about health and 26 about rehabilitation are our rights and terms of reference in support of our Post Polio policy. The walls around Jericho are of course not tumbling down just by quoting these articles but they provide us with arguments for justification of our policy which cannot easily be put aside. More arguments of medical, social and statistical nature are also needed, but the UN Convention gives us a legally speaking sound case.

So we don't have to invent all arguments and to start from scratch. On the contrary we can base our Post Polio policy legally on the UN Convention and medically, socially and by means of rehabilitation on the good experiences developed especially in the Nordic countries, in the Netherlands and elsewhere in Europe.

We need to agree on an EPU strategy for developing a programme leading to a fulfilment of the above mentioned goals; research, rehabilitation, training and a development aid programme.

2. A research programme

A scientific Post Polio committee has to be established in the EU. This committee shall be a coordinator for research activities in the field of Post Polio. The committee shall act as a centre, where all medical knowledge about Post Polio shall be registered in a database at disposal for all doctors and other health personal and to the public as well.

The committee shall also act as an information centre spreading news about the latest research results and initiatives sending out newsletters to members and subscribers.

For interested health professionals one might also host regular telephone conferences taking up questions and themes which the committee considers to be of special interest.

The committee shall also try to make the centre part of other similar networks in the US and elsewhere aiming at establishing a global Post Polio network.

One of the first challenges shall be to give a valid description of the Post Polio diagnosis, prognosis and best practice for rehabilitation and recommended life style for Polio Survivors.

3. A Post Polio rehabilitation programme

EPU shall adopt a plan of action leading to developing of a standard rehabilitation programme for Polio Survivors.

When it comes to rehabilitation a close cooperation between doctors and physiotherapists is absolutely needed.

The goal is to secure, that such a rehabilitation programme primarily is made well known and accepted by doctors, physiotherapists and other health personal in all EU member states but also realized in practice so that all Polio Survivors have access to such a rehabilitation programme

It is also needed to identify at least one national rehabilitation centre for Polio Survivors in each member state hopefully as a special clinic or unit at a major university hospital.

An initial step is to find doctors and other health professionals with various relevant backgrounds, who are interested in working with Polio victims in each member state, making them form a network with the mission to develop the above mentioned Polio centres.

4. An international development aid programme for Polio Survivors in the third world

In the UN Disability Convention CRPD article 32 one find a rule about international cooperation. Implementation of this rule for Polio Survivors ought to be an important goal for the EU. EPU should take this up lobbying for our brothers and sisters with Polio impairment in developing countries giving them better and more equal opportunities in their home countries. Obviously they need support much more than we do in the EU.

EU is one of the major global international donors. The resources are available, but EPU has to influence the distribution, so that Polio Survivors are given the priority and share they need of EU-development aid.

The Scandinavian development agencies, Danida, Sida and Norad are also possible donors, which might contribute.

So far vaccination against Polio with good reason has been given top priority aiming at “Ending Polio Now” as the Rotary International programme is called. The goal to eradicate Polio has almost been achieved and seems to be within reach in a few years from now. But millions of Polio Survivors so far have been left to fight for themselves. Few if any have cared for them. Is that not now a worthy challenge to take up for the EPU?

5. Conclusion

EPU cannot expect to be seen and recognized as an important NGO if we don't make EPU visible as an active disability organization with an agenda which is relevant to politicians and to the public as well as for our members.

EPU therefore has to consider the above mentioned proposals carefully and to elaborate a plan of action in which they need to be the pillars on which the future work of our organization shall be founded.

We have to establish a working group, which shall draw up a programme for each of the main goals answering the questions who, how and when:

- Who shall draft and run each of the programmes?

A small dedicated hard working drafting committee is needed

- How shall we raise funding for the programmes?

The EPU board has to adopt a fund raising programme

- When are we ready to act – a timetable is needed?

Also that issue is a job for the EPU board

Each of the three goals might be achieved separately and might also be worth working for uncoordinated, but united they become a strategy, which takes care of all Polio Survivors both within and outside of the EU. EPU should not be seen only as an egoistic NGO looking after its own members, but also as an idealistic organization demonstrating solidarity with Polio Survivors at a global level.

If we act accordingly EPU shall have a good common cause to fight for and in that way prove to be worthy of respect from the public as well as from possible donors without whom EPU cannot achieve any of the goals which I have focused on in this short intervention.

Thank you for your kind attention.

H. Kallehauge, Roedovre, August 2011

HEALTH COSTS FOR POLIO SURVIVORS

Whilst at the Copenhagen Conference a late night discussion between some of the health professionals and those involved in the voluntary sector organisations who care for Polio Survivors turned to the question of whether health costs for Polio Survivors are greater than those for others in the population of a similar age and circumstance but have not suffered a period of paralytic Poliomyelitis.

Therefore it was decided to initiate a small research project, paper-based, that would ask questions across the world as to whether there is any definitive data showing additional costs attached to Polio Survivors' disabilities. A volunteer from the Irish group has written out to many countries across the world using contacts not just from Copenhagen but also from the World Health Organisation asking the question regarding costs.

To date although the response has been encouraging the data is extremely scarce with the only places able to give hard evidence being an area of Italy and that in Western Australia.

If any organisation within the EPU has any information could they please send it through to the following e-mail address chairman@ppsg.ie. The information required compares the standard health costs of a healthy person of say 60 to 65 years old who has not suffered a period of paralytic Polio compared to the health costs of a person of the same age that has suffered a period of paralytic Polio and/or has Post Polio Syndrome.

The results of such research will allow the EPU to make a case through the European Commission and European Parliament to encourage all member states to recognise additional costs incurred by those who had a period of paralytic Polio and who now are incurring additional costs caused by this. Although all member states have their own Social Welfare arrangements any centralised pressure that may be applied from Brussels to national governments could well be of assistance in alleviating hardship experienced by those who had Polio many years ago so allowing them today to live with dignity and independence.

EUROPEAN PLATFORM FOR REHABILITATION

Angela Kerins, Chief Executive of the Rehab Group, has been elected President of the European Platform for Rehabilitation (EPR), a European wide network of leading providers of services to people with disabilities and others who are disadvantaged. Ms Kerins is the first woman to hold this position. The EPR has a seat on the EU's High Level Group on Disability and has participatory status with the Council of Europe.

Ms Kerins said "I am delighted to take on the presidency of the EPR at this exciting time in its development. We intend to continue to lead innovation and change and to act as a forum for creative thinking, through the development of pioneering and entrepreneurial solutions to the challenges and opportunities of today – not just letting the future happen, but creating it!"

"Social innovation is the cornerstone of the not-for-profit sector and over many decades the sector, through its mini member organisations across the globe, has spearheaded social change and achieved pioneering successes. Social innovation is now more important than ever and we must do all that we can to encourage and drive progress. When a large number of people are energised, things happen. It is our responsibility not only to ensure that our people's lives are energised but that what they produce makes a real difference to people's lives."

The EPU has written to Ms Kerins congratulating her on her appointment as much of the work of the EPR resulted from rehabilitation clinics and processes arising from the Poliomyelitis outbreaks of the 40s and 50s. There is synergy between their work and that of the EPU and their goals in allowing people with disabilities to live with dignity and independence reflects our own ideas and objectives. It is to be hoped that at some stage in the future Ms Kerins may be able to meet with us to discuss matters of mutual interest.

SIPS Switzerland

News has been received from our Swiss member organisation that Dr Thomas Lehman has had to retire as their president due to health problems. We all wish him well and are pleased that he will be remaining as a Board Member of the Swiss organisation.

The board of SIPS Switzerland has elected Mrs Erika Gehrig as their new president, her contact details and that of Thomas Lehman are shown below and it is asked that your records are amended accordingly.

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NEWS FROM BRUSSELS

LAUNCH OF THE WORLD REPORT ON DISABILITY AT THE EUROPEAN PARLIAMENT

On 7th December 2011 the first ever World Report on Disability, produced jointly by WHO and the World Bank, was presented and discussed at a launch event in the European Parliament. This high-level debate was hosted by MEP Ádám Kósa (Chair of the Intergroup

on Disability) and concluded by Commissioner László Andor, Commissioner for Employment, Social Affairs and Inclusion. Speakers included:

- Laszlo Andor - Commissioner for employment, social affairs and inclusion
- Olivér Várhelyi - Ambassador, Deputy Permanent Representative of Hungary to the EU
- Tamar Manuelyan Atinc - Vice President for Human Development, World Bank
- Martin Krayner von Krauss - WHO, Project manager
- Lars Bosselmann - Advocacy Manager, CBM
- Javier Güemes - Acting Director, European Disability Forum (EDF)

All speakers welcomed the release of the World Report on Disability, as it assembles the most up-to-date data on disability globally. It also contains a set of recommendations that will help to guide policy decisions. The Report brought us new estimates of the prevalence of disability - there are an estimated one billion people with disability globally, the vast majority of these living in developing countries.

"This underlines once again that disability is a development issue that needs to be much higher on the agenda of international cooperation" declared Lars Bosselmann. "And the EU can play a crucial role in promoting the rights of persons with disabilities in international cooperation. The upcoming negotiations on a new global agenda for development constitute an excellent opportunity to do this" said both Javier Guemes and Lars Bosselmann.

The way forward

The World Report on Disability is an important tool to implement the UN Convention on the Rights of Persons with Disabilities, ratified by the EU.

In moving forward, it is critical that persons with disabilities themselves can make their voice heard in all decisions that concern them. Furthermore, the expertise of a wide range of stakeholders - ranging from political institutions to civil society - have to be combined, in order to meet the huge challenges of persons with disabilities across the globe.

PRESIDENTS BARROSO, BUZEK & VAN ROMPUY MEET WITH EDF: THE FIRST STATE OF THE UNION ON DISABILITY – 6 December 2011

This is the first human rights treaty concluded by the EU. It promotes the full participation of persons with disabilities in the society, including women and children with disabilities and their families. In this challenging time of crisis, persons with disabilities in Europe are among the worst hit by the unprecedented austerity measures taken by governments.

As the President of the European Commission José Manuel Barroso stressed: “The crisis



shouldn't prevent us from advancing in the implementation of the UN Convention. There won't be any postponed legislation because of this crisis.”

Jerzy Buzek, President of the European Parliament reaffirmed the Parliament's commitment to implement the UN Convention. “I am calling for the

conclusion of the Optional Protocol by the European Council” he added.

This was the first meeting of a series of State of the Union on Disabilities that will now happen every two years. The main goal of this Presidents’ meeting is to make sure the European institutions are working together towards the implementation of the UN Convention on the Rights of Persons with Disabilities concluded in 2010.

As President Van Rompuy observed on decision making, “When we discuss macroeconomic policy, we tend to forget concrete situation of persons with disabilities.” Therefore EDF requested to have a presentation at the European Council about the effects of the economic crisis. President Van Rompuy also stated, “A social way out of the crisis is possible”.

Yannis Vardakastanis, President of the EDF stressed: “Today, in a time of profound crisis, the commitment to respect and promote the UN Convention is not enough. We ask for the rapid and practical implementation of this Convention through which real change of the lives of persons with disabilities need to be delivered. The State of the Union on Disability is a unique opportunity for the EU leaders to put in place all the necessary policies and measures to make the European Institutions work for the real protection and promotion of the rights of persons with disabilities. This is the only practical way to combat poverty, discrimination and exclusion and to promote the inclusion of 80 million Europeans with disabilities working together for more freedom, participation, democracy and human rights.”

EDF executive committee members have reminded the EU Presidents the importance of the EU action in many areas such as the Structural Funds; the access to technology, to built environment and to transport, the people in need of high levels of support, gender equality and social services for persons with disabilities.

EDF brought a series of proposals and welcomes the commitments and positive response that came out of the meeting:

- the EDF participation to one meeting of the college of Commissioners in 2012
- the involvement of EDF in one of the meetings of the European Commission General Directors meeting in to ensure the horizontal implementation of the UN Convention
- the 2012 European Parliament of the persons with disabilities widely supported by President Buzek and by MEP Adam Kosa, President of the Disability Intergroup that also participated in the meeting.

Vice President of the European Commission Viviane Reding reiterated her commitment for a strong European Accessibility Act which is part of the Disability Strategy.

EDF welcomed the promise given by President Barroso to gather again the leaders of the disability movement and the EU Presidents in two years to check the results of the progress. On behalf of the 3 Presidents of the other institutions, Jose Manuel Barroso stated that “The European Disability Forum is the primary interlocutor in Europe for disability issues.”

EPU Countries & Member Organisations

- **BELGIUM:** Post Polio Belgium
www.postpolio.be
- **BELGIUM:** Association Francophone Polio&Post-polio (AFPPP)
www.afppp.be
- **BELGIUM:** Association Belge des Paralysés (ABP)
www.abpasbl.be
- **DENMARK:** Landsforeningen af Polio-, Trafik- og Ulykkeskadede (PTU)
www.ptu.dk
- **FINLAND:** Suomen Polioliitto Ry
www.polioliitto.com
- **FRANCE:** Groupe de Liaison et d'Information Post-Polio
www.post-polio.asso.fr
- **GERMANY:** Bundesverband Polio e.V.
www.polio.sh
- **GERMANY:** EIKA Aachen Polio-Forum (Associate Member)
www.polio-forum.de
- **GERMANY:** Polio Selbsthilfe e.V.
www.polio-selbsthilfe.net
- **ITALY:** AIDM Onlus - Associazione Interregionale Disabili Motori Onlus
www.aidmonlus.it
- **IRELAND:** Post Polio Support Group (PPSG)
www.ppsg.ie
- **NETHERLANDS (The) :** (Post)Polio Group from the VSN (Vereniging Spierziekten Nederland)
www.vsn.nl
- **NORWAY:** Landsforeningen for Polioskadde
www.polionor.org
- **SCHWEIZ/SWITZERLAND:**
Schweizerische Interessengemeinschaft für Poliomyelitis Spätfolgen
(SIPS)(Deutsch/German)
Communauté Suisse d'intérêt pour les suites tardives de la poliomyélite (CISP)
(Français/French)
Comunità Svizzerad'interessi dei postumi tardivi della poliomielite (CSIP)
(Italiano/Italian)
www.polio.ch
- **SPAIN:** Asociación Afectados de Polio y Síndrome Postpolio
www.postpolioinfor.org
- **SPAIN:** Associats de Polio I Postpolio de Catalunya (APPCAT) (Associate Member)
www.appcat.org
- **SWEDEN:** Riksförbundet för Trafik-, Olycksfalls – och Polioskadade (RTP)
www.rtp.se
- **U.K.:** The British Polio Fellowship
www.britishpolio.org.uk
- **U.K.:** Polio Survivors Network
www.poliosurvivorsnetwork.org.uk

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