CEE GN Central & Eastern European Genetic Network

Working together for a voice in research & health policies and benefiting from genetics, genomics & biotechnology

CEEGN Annual Board Meeting & General Assembly

Minutes Meeting

Prague, Orea Pyramida Hotel

24th – 25th January 2009

Participants

Detailed list of participants including the contact details is attached to the Minutes (Attachment 1).

CEEGN Board Members:
Grzegorz Wegrzyn, Poland (President)
Rumen Stefanov, Bulgaria
Radostina Simeonova, Bulgaria
Boris Sustaric, Slovenia
Tereza Matulka, Poland
Osman Sinanovic, Bosnia

CEEGN Honorary Members:
Ysbrand Poortman, The Netherlands
Selena Freisens, Germany

Patient Organizations Representatives:
Coskun Ozdemir, Turkey
Hakan Ozgul, Turkey
Gokhun Cetin, Turkey
Loredana Tascau, Romania
Marica Miric, Croatia
Maryze Schoneveld van der Linde, The Netherlands
Tanneke van der Linde, The Netherlands
Triin Suvi, Estonia
Violeta Antonova, Bulgaria
Neli Kostadina, Bulgaria
Justyna Matulka, Poland
Malgorzata Kaflik, Poland
Svetlana Karimova, Russia
Zdenek Janda, Czech Republic
Petr Prochazka, Czech Republic
Jitka Kacirkova,Czech Republic
Dona Jandova,Czech Republic
Miroslava Procházková,Czech Republic
Vera Kacirková, Czech Republic
Katarina Stepankova, Slovakia

Guests representing Projects, and other organizations:
Alex McKeown, UK
Cor Oosterwijk, The Netherlands
Ingrid Klingmann, Germany
Frank Wells, UK
Stéphanie Hoffmann, Belgium
Julie Kjestrup, Belgium
Fanny Senez, Belgium

Meeting Organization:
Ysbrand Poortman, Maryze Schoneveld van der Linde, Selena Freisens, Alex McKeown

Agenda

- Opening/welcome/ determination agenda
- Tour de table
- State of the art & report over 2008
- Constitutional affairs
    - approval minutes of the AGM in Basel, January 2008
    - approval report 2008 & budget
    - approval Policy and Action plan
    - appointment and dismissal of Members of the Board
- Determination of common needs and priorities in the CEEGN- landscape
- Tentative action plan in general
    - vision, mission/ambition, profile, position.
    - manifesto/declaration
- Participation in EU and other projects
- Representation and participation in the European Genetic Community
    - opportunities, benefits, obligations and implementation
- Capacity building and acquiring human and financial resources
- Executive affairs/ Proposal for CEEGN actionplan
- Membership and membership outreach
- Any other business
- Conclusions / summary decisions/ closure

Discussions and Action points

1) CEEGN Board and Membership

- **Radostina Simeonova** is appointed Executive Director CEEGN.
  Radostina is a manager of a Centre for physical and rehabilitation medicine in Plovdiv. She graduated medicine and is currently finalizing master degree in healthcare management. Radostina is also a volunteer-consultant at the Information Centre for Rare Diseases and Orphan Drugs (ICRDOD), member of the Bulgarian Association of Physical and Rehabilitation Medicine (BAPRM) and World Association for Laser Therapy (WALT). She speaks 4 languages; Bulgarian, English, Russian and some German.

- **Neli Kostadinova** is appointed as the CEEGN Treasurer. The financial operations will be transitioned to Bulgaria effective immediately.

- **Osman Sinanovic** is appointed new Board Member of CEEGN.

- **Susan Szendro,** Board Member and the secretary of CEEGN , the president of the Hungarian National Genetic Alliance, will retire due to unexpected health problems. Susan will remain the member of the CEEGN, without taking any active role. The replacement from Hungary will be suggested. The secretariat will be transferred to Bulgaria effective immediately.

- **The Board invited all participants to become members of the CEEGN.** Through the CEEGN, the members will be able to take part in different European Projects and will be able to raise the voice from their countries on the EU level; they will receive the newsletters and will be up-to date on activities ongoing on the European level, as well as on activities of CEEGN. The members will get support from CEEGN for local endorsements, such as for example letters to governments; support to increase awareness and knowledge on genetic disease in the country; building up the information center. CEEGN doesn't require a membership fee, this is compensated through voluntary engagement by the members.

2) Challenges in CEE countries

1. **Lack of Reimbursement**
   There is a need for more transparency over reimbursement decisions and reimbursement programs. The patients are encouraged to become members of the Parliament to be able to influence the decisions, including the ones on the healthcare budgets. It was highlighted that the goal of CEEGN is "prevention" , which is the way to save the costs of disease treatment and disease management.

2. **Lack of Information on genetic and Rare disease/ luck of infrastructure for follow up of diagnosed patients**
   See page 4, point 3

3. **Language barrier**
   Common in CEE countries. There is a need for websites and all other information tools to be translated in different eastern European languages. Google translate can be used as a tool to obtain translation in most of languages, though the translation is not perfect and require check up.

4. **Collaboration with TV/ Media**
   Participants criticized the media, who often wrongly interpretates the information ("they just want to make a sensation") and therefore brings false news about the health and scientific developments to the public, as well as to the patients. This is seen not only as the situation in the CEE countries, but also as the major global issue. The members of EFGCP have been asked to take action.

   The collaboration with journalists and media is highlighted as very important to prevent this irresponsible behavior of the media. As a good example for collaboration with the media has been presented by the Polish patient organizations –they make friendships with journalists, invite them to the family meetings to " show them our lives".
   In Turkey, it was noticed that the statement from an international organization would help to avoid false information on TV and in the media. Eventually CEEGN should consider to provide such statements in the future where needed.

3) CEEGN Plan 2009

- The presented Plan was adopted by the Members – see attached Plan for reference. The Events list will be updated to include some additional major events as suggested by the participants.

- One of the main CEEGN goals is to strengthen the organization, through
  1) Strengthening the network and increasing the number of members
  2) Participation in EU events and Projects

  Actions aiming to strengthen the organization

- Improving internal communication among current CEEGN members

- Enlarging the organisation by identification and contact with new potential members from Central and Eastern European countries
- Update of CEEGN website with:
  - News from member countries, updated monthly
  - Members login section
  - Educational materials for patients and organisations
  - Sharing best practices in each country
  - Calendar of events
  - Forum
- Printing and distribution of promotional flyers, business cards etc.
- Communication with other organisations with adjacent goals (eurordis)
- Fundraising activities (letters to industry)
- Creation of a project writing team within CEEGN or in collaboration with other NGOs
- Planning and organisation of annual CEEGN meetings (on rotation principle)

3) Medical Board of Advisors

The invitation for membership to the CEEGN Medical Board of Advisors will be distributed accordingly to the below nominated physicians:

- Prof. Dr. Mirando Mrsic, Croatia
- Prof. Dr. Alexey Sokolov, Russia
- Prof. Dr. Radka Tincheva, Bulgaria
- Prof. Anna Tylki-Szymanska, Poland
- Prof. Coskun Ozdemir, Turkey
- Prof. Milan Macek, Czech Republic
- Prof. Wladimir Wertelecky, Ukraine
- Prof. Borut Peterlin, Slovenia
- Dr. Czaba Siffel, Hungary
- Dr. Mariana Serbanescu, Romania

4) CEEGN Priority Projects 2009

CEEGN Board presented 3 major projects defined as the common gaps in the CEE region, in which CEEGN wants to take the lead, and focus to tackle those issues through its activities. The workgroups have been formed from the volunteers to work on those projects

1. Preconception care- folic acid prevention in CEE countries

Folic acid is proven to prevent birth defects such as spina bifida. In western EU countries prevention with folic acid before and during pregnancy has become a practice in many countries and is included in the government awareness and reimbursement programs. In majority of CEE countries, however, this is not yet the case, hence the awareness of importance of folic acid is still very low among population, including physicians, and the costs are not covered by the government. The objective of the CEEGN Pre-conception Workgroup is 1) to provide the inventory of current situation in the countries, 2) prepare an action plan and 3) endorse activities on folic acid prevention in the CEE countries where this is needed. The Work group members:

- Rumen Stefanov
- Selena Freisens
- Katarina Stepankova

2. Neonatal screening in CEE countries

Neonatal screening as well as the early diagnosis have enormous importance in prevention of the disease. Especially high importance is in the CEE region where frequent misdiagnosis are reported. The CEEGN should prepare the statement on the topic of neonatal screening, including the notice that "we intend to extend the neonatal program and screening services to Central and Eastern European countries".

The International Society for Neonatal Screening is starting the program to increase the number of screened diseases to up to 18 (currently only 6 are included). At a minimum, treatable diseases should be included. EGAN is invited to collaborate with the scientific committee, CEEGN can also participate. The 6th ISNS European Regional Meeting on Neonatal Screening will take part on April 26th-28th in Prague, Czech Republic. It was agreed that the CEEGN Workgroup on Neonatal screening should take part in this event and report back to the group:

- Neli Kostadinova
- Marica Miric

Cor received the contact details of both Neli and Marica and will contact them accordingly to invite them to the meeting in April.

3. Improving awareness and information in CEE countries

The information is seen as a common need in all countries. Reported is lack of information about the disease, diagnosis, available treatments. There is no guidance for patients after diagnosis, patients do not know where to go, whom to contact, etc. Some (if not many) patients get lost for follow up, there is usually no tracking system in place. In some countries genetic consultation on the one hand is not reimbursed and on the other too costly for private pockets. Language barrier usually unables the patients to search for information in the internet. The relationship between the patient and physician is seen as good, but physicians have no interest to increase their knowledge and to keep updated with ongoing scientific developments (also due to language barriers) in rare/ genetic disease field.

In Bulgaria, the Information Centre for Rare Diseases and Orphan Drugs (ICRDOD) has been established as a NGO and functions successfully since several years. One of the main goals of this center is to facilitate the access of patients with rare diseases to information about the disease, and provide medical professionals with quality information about rare diseases. The center is financed by projects and donations. Besides the information services, ICRDOD organized and lobbied for creation and adoption of National plan for rare diseases, finally approved by the Bulgarian government with a total budget of approximately 11M euros for 2009-2013. For further information see www.raredis.org. Available in several languages.

As a middle-long term goal, the CEEGN will streamline its activities to support building up the "local information centers in countries of CEE" where those centers are not existing and are needed to improve the care of patients with genetic and rare disease.

Workgroup members:

- Coskun Ozdemir
- Rumen Stefanov
- TBD

CEEGN looks for volunteers for this Workgroup. The participants are requested to follow up with the members of their patient organizations and inform back if there are additional volunteers for this project.

5) Other ongoing Projects and CEEGN Members Responsibilities

EPPOSI

It was agreed that Radostina who is an executive director CEEGN will participate in EPPOSI meetings to represent the CEEGN.

Roche/ EGAN collaboration

Rumen and Grzegorz will continue to represent CEEGN in this affairs.

EuroGenGuide / EuroGenTest

Selena, Rumen and Grzegorz will continue to attend and follow up on this projects on behalf of CEEGN.

Fundraising campaigns
Top priority for CEEGN, as resources are needed to enable meetings and activities such as website adaptation, leaflets production, etc. The fundraising letter will be distributed to several industries immediately. The CEEGN Board members highlighted importance of participating in the European Projects which is generating the financial compensation in return. For example, the CEEGN Meeting in Prague is financed 50% though the EuroGenGuide budgets. CEEGN will continue to search for becoming a partner in upcoming EU projects.

Support to National Genetic Networks in each CEE country

As ultimate goal, the CEEGN aims to support existing national genetic networks in the CEE countries, as well as creation of the new national genetic networks. Ysbrand Poortman very clearly explained the positioning of Genetic Network Organizations vs. Rare Disease Organizations (for example Eurordis). Roughly: The CEEGN focuses on EARLY stage → "disease prevention" and "research and development", while Eurordis focuses on LATER STAGE → "treatment, care" and "treatment access policy".

6) European Projects

1. Eurogenguide (Alex McKeown)

CEEGN is an official member of the Eurogenguide project (www.eurogenguide.eu), and also takes part in the Eurogentest project (www.eurogentest.org). The Eurogenguide focuses to bring *information manual* on genetic services (for example on biobanks, genetic testing, patient consent forms, etc) for patients, their families and general public, and also for health professionals. It is a 3 year EU- funded project. This year is the last year, and main goals are to finalize and launch the program. The finalization is planned in October, and the launch in December (eventually in Warsaw). After that, the awareness and distribution of program deliverables will be crucial.

It was notified that for CEE countries a printed version of the Manuel is important, as many patients still do not have the internet access. There is also a language barrier, therefore the printouts/ website should be translated in the local languages.

The Eurogenguide will produce a "short" version for print. It also offers google translate on the website in most of the languages, but not in Turkish. The group suggested to include the short version as "pdf" in Turkish language into the website. The final print version will be available in May. CEEGN will take the lead role in coordinating the preparation of the local printed versions. The participants will be contacted for support with regards to check the translation. The next EurogenGuide meeting is planned in Vienna in May 09, in conjunction with the ESHG conference.

2. PatientPartner: Patient participation in clinical trials (Cor Osterwijk)

EU Project running from May 2008- May 2011, with goal to stimulate active Patients involvement in clinical trials.
In 2008, a questionnaire was distributed Europe –wide.
In the 2nd year (2009) 5 workshops throughout Europe will be organized with participation of all stake holders. A 2-day regional workshop is planned for CEE representatives (10th-11th September 2009 in Budapest). 20 patients from CEE will be invited. European Genetic Alliances Network will set up a broad patient network for this EU-FP 7 project.

The outcome of the workshop is to produce a Guide for Patients on how to get involved in the clinical trials. There will also be Investigator Guide for trial organizations as well as the List of Recommendations for regulators.

The website is in development, it will be a thematic website (for example connect patients with industry end vice versa). As a WP 3, the European Network of Patients Partnering for Clinical Research (EN-PCR) organizes a virtual network of patients.

Cor Osterwijk, who is the project coordinator will keep CEEGN members in the loop and inform about possibilities for involvement & participation in clinical research and finding the specific needs in different countries of CEE. Those who are interested to participate in this project (and workshop in Budapest) should contact directly Cor, or the CEEGN.

3. Roadmap to treatment (Ingrid Klingmann, Ysbrand Poortman)

Ingrid Klingmann, chair WP and board member EFGCP gave an update on the achievements and together with Ysbrand Poortman shared the program for 2009/2010. It was suggested to participate in this project by participating in the working parties and the organization of "patient day" events in the member countries which are to be held in the native language as proposed by the members and adapted to specific patient groups.

The flyers and reports are available. The Road Map partners closely with Patient Partner, and IMI.
New meetings are planned covering following topics: "your contribution to drug development for your disease" and "patients – the driving force for clinical trials in Europe".

The Patient Day

Project for patients and other stake holders to get the basic knowledge on the clinical trials.
The CEEGN participants suggested to choose another name for the project - given the fact that the program is not aiming only at patients, the name can be misleading.

Potentially the "Patient Day" workshop can be organized in conjunction with the next CEEGN annual meeting in January 2010. This will help to split the costs for organization, but there is also an opportunity for CEEGN to extend the network. The CEEGN members will re-approach Ingrid well before the annual meeting to allow enough time for planning.

4. Public training

Integrated Medicine Development (IMD) project - a 5 year project – will organize training courses for non-specialists on drug invention and pathway to drug development. Patients are working together with science and industry in this project. The courses are targeting journalists, politicians, venture capitals, patient associations, ethics comities, non-clinical industry stuff.

Phases:
2009 - 2010 – Phase learn
2012 - 2014 Phase confirm and sustain

The additional objective of the project is to support local multi-stakeholder dialogue. The courses will be made in local language. Local countries will have to take the responsibility for the organization. The budgets are limited (also only to EU countries!). For more information visit www.biomedinfo.com.

Ingrid Klingmann and Ysbrand Poortman take the responsibility for this project. The project will have the "Regional contact node", hence the CEE can be considered as a separate Region. The CEEGN will remain the main contact to suggest participation of the members interested to organize the course in their counrties.

5. Treat-NMD

Maryze Schoneveld van der Linde explained this project, and her personal experience in involvement of drug development for Pompe disease. The Treat-NMD is the network of people with neuromuscular disease and professionals working on it. It aims to advance diagnosis and care and develop new treatments for the benefits of patients and families, working together with scientists, healthcare professionals, industry and patients around the world. This close collaboration has great importance to facilitate drug development, therefore all patients are encouraged to get involved and establish the collaboration with other stake holders.

The Patient Registries are highlighted as one of the important pre-requisites for patients' active involvement in research and development of drugs.

The Treat NMD/ NIH conference: “Bringing down the Barriers - Translational Medicine in Inherited Neuromuscular Diseases”, will be held on 17 – 19 November 2009 in Brussels, Belgium (www.treat-nmd.eu)

7) Other issues

Health Economics for Orphan diseases

The participants actively discussed current intentions of Health Authorities in some countries to implement Health Economic value to orphan diseases and treatments. For example, in Poland, the Committee for Evaluation of Health Economic Value of Treatment, is currently working to implement this evaluation on orphan drugs. The overall opinion is that orphan drugs should be excluded from this procedure, and that this evaluation does not take into consideration ethics, and ethical values.

The CEEGN should prepare the official public statement on this topic. The statement should include “it’s not our fault for having a rare disease” and “appropriate drug on time = cost saving + health benefit”. The costs are higher and benefits are lower if the drug is given too late.

CEEGN may consider to take over some already available statements from other organization, for example IGA and EGAN.

EuropaBio (Julie Kjestrup)

EuropaBio representatives are welcoming partnering and collaboration with Patient Organizations in the countries of CEE on issues regarding the treatment development. EuropaBio has contacts in 25 European countries, including the CEE Region.

CEEGN was invited to be a member of EuropaBio Patient Advisory Council. The CEEGN is welcoming for this opportunity. Radostina, who will to represent the CEEGN, will get back to Julie accordingly to receive further details of participation.

8) CEEGN meetings and Events

The Board will plan its next meeting in Plovdiv in conjunction with the "4th Eastern European Conference on Rare Diseases and Orphan Drugs". Rumen can offer space for the workshop/ meeting.

CEEGN plans to attend the ESHG conference in May in Vienna, ongoing together with the EGAN assembly meeting.

The next annual Board and Assembly meeting will be planned for end of January 2010.

The Participants are welcome to apply and take part in any of the CEEGN meetings and events, as described in the CEEGN event list. The Participants are also kindly asked to share any national important event on genetic and rare disease, where eventual presence and participation of CEEGN would be of relevance.

The list of events where CEEGN plans participation is attached in *Attachment 2*.

Attachment 1

List of Participants

	List of Participants, Prague 24th-25th January 2009			
	Name	**Organisation**	**Country**	**Email**
1	Osman Sinanovic	Neuromuscsular Association University Clinical Center Tuzla;	Bosnia	osman.sinanovic@ukctuzla.ba
2	Coskun Ozdemir	Turkish Neuromuscular Diseases Association	Turkey	coskunoz@superonline.com
3	Hakan Ozgul	Turkish Neuromuscular Diseases Association	Turkey	ozgulhakan@hotmail.com
4	Gokhun Cetin	Turkish Neuromuscular Diseases Association	Turkey	ygc1980@yahoo.com
5	Radostina Simeonova	ICRDOD; Clinic of Paed. Diseases "Alexandrovska" Univ. Hosp. Sofia	Bulgaria	simeonova@raredis.org
6	Rumen Stefanov	Information Centre for Rare Diseases and Orphan Drugs (ICRDOD)	Bulgaria	stefanov@raredis.org
7	Grzegorz Wegrzyn	MPS Patient Association Poland; CEEGN	Poland	wegrzyn@biotech.ug.gda.pl
8	Loredana Tascau	Romanian League for Mental Health	Romania	lrsm@clicknet.ro
9	Selena Freisens	Central Eastern European Genetic Network - CEEGN	Germany	infofreisens@arcor.de
10	Ysbrand Poortman	IGA, EGAN, WANDA, CEEGN	The Netherlands	ypoortman@zonnet.nl
11	Marica Miric	Saveza Drustava Distroficara Hrvatske	Croatia	soih@zg.t-com.hr
12	Maryze Schoneveld van der Linde	International Pompe Association (IPA), WANDA	The Netherlands	maryze@xs4all.nl
13	Tanneke van der Linde	International Pompe Association	The Netherlands	maryze@xs4all.nl
14	Boris Sustaric	Društvo Distrofikov Slovenije	Slovenia	info@drustvo-distrofikov.si
15	Triin Suvi	The Estonian Association of Muscular Disorders	Estonia	triin.suvi@ut.ee
16	Violeta Antonova	Bulgarian Neuromuscular Diseases Association	Bulgaria	banmz@abv.bg
17	Neli Kostadina	Bulgarian Neuromuscular Diseases Association	Bulgaria	banmz@abv.bg
18	Tereza Matulka	MPS Patient Association Poland; CEEGN	Poland	tmatulka@wp.pl
19	Justyna Matulka	MPS Patient Association Poland	Poland	tmatulka@wp.pl
20	Malgorzata Kaflik	MPS Patient Association Poland	Poland	mkaflik@wp.pl
21	Svetlana Karimova	National Association of Organization of Patients with Rare Diseases	Russia	angel_sv@mail.ru; nacgenetic@mail.ru
22	Zdenek Janda	Asociace muskularnich dystrofiku v CR	Czech Republic	zdenek.janda@volny.cz
23	Petr Prochazka	Asociace muskularnich dystrofiku v CR	Czech Republic	
24	Jitka Kacirkova	Asociace muskularnich dystrofiku v CR	Czech Republic	
25	Dona Jandova	Asociace muskularnich dystrofiku v CR	Czech Republic	
26	Miroslava Procházková	Asociace muskularnich dystrofiku v CR	Czech Republic	
27	Vera Kacirková	Asociace muskularnich dystrofiku v CR	Czech Republic	
28	Katarina Stephankova	Cystic Fibrosis Association	Slovakia	kstep@stonline.sk; kstep@ke.telecom.sk
29	Alex McKeown	EuroGenGuide / Genetic Interest Group - GIG	United Kingdom	alex@gig.org.uk
30	Cor Oosterwijk	Patient Partner/ European Genetic Alliances Network (EGAN)	The Netherlands	c.oosterwijk@vsop.nl
31	Ingrid Klingmann	European Forum for Good Clinical Practice (EFGCP)	Germany	nippert@uni-muenster.de
32	Frank Wells	European Forum for Good Clinical Practice (EFGCP)	UK	
33	Stéphanie Hoffmann	Genzyme	Belgium	stephanie.hoffmann@genzyme.com
34	Julie Kjestrup	EuropaBio	Belgium	j.kjestrup@europabio.org
35	Fanny Senez	European Forum for Good Clinical Practice (EFGCP)	Belgium	fsenez@efgcp.be

Attachment 2

CEEGN Events List 2009-2010

Event	Place	Date	Organizers	Participants oin behalf of CEEGN	Website
CEEGN Annual Board and Assembly Meeting, in conjuntion with EFGCP conference	Prague	January 24-25, 2009	CEEGN/ WANDA	CEEGN Board and Assembly, WANDA, IPA, EGAN, EFGCP, EuropaBio, PatientPartner, EuroGenGuide	www.ceegn.org
The 6th ISNS European Regional Meeting on Neonatal Screening	Prague	April 26-28, 2009	EGAN	Neli Kostadinova; Marica Miric	www.isns-neoscreening.org
European Society of Human Genetics conference (ESHG), EGAN assembly, EuroGenGuide	Vienna	May 24 - 26, 2009	ESHG/EGAN/ AGM/ GIG	TBD	www.eshg.org;www.egan.org
8th Balkan Meeting on Human Genetics	Cavtat	May 14-17, 2009	Croatian Society of Human Genetics, Croatian Society for Rare Diseases, Croatian Medical Assoc.	TBD	www.studiohrg.hr/human-genetics2009
10th European Symposium Prevention of congenital anomalies	Bilbao	June 10, 2009	EUROCAT	Barbara Czeisel (tbc)	www.eurocat2009.com
4th Eastern European conference on rare diseases and orphan drugs; CEEGN Board Meeting	Plovdiv	June 13-14, 2009	ICRDOD / DG SANCO	Rumen Stefanov, Radostina Simeonova	www.raredis.org
Patient Partner Workshop in CEE	Budapest	September 10-11, 2009	EGAN	TBD	www.efgcp.be
EPPOSI	Brussels	October-09	EPPOSI	Radostina Simeonova	www.epposi.org
EuroGenGuide	Warsaw (tbc)	December-09	GIG	Selena Freisens, Rumen Stefanov	www.eurogenguide.eu
CEEGN Annual Board and Assembly Meeting	TBC	January-10	CEEGN	CEEGN Board and Assembly, TBC	www.ceegn.org
European Society of Human Genetics conference (ESHG)	Gothenburg	June 12-15, 2010	ESHG	TBD	www.eshg.org;
TREAT-NMD/NIH international conference	Brussels	17 – 19 November 2009	Treat NMD/NIH	TBD	www.treat-nmd.eu

Group Photo, Prague, January 2009