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Workshop report

231st ENMC International Workshop: International Standard for CIDP Registry and Biobank, Naarden, The Netherlands, 12–14 May 2017

Filip Eftimov [a,*], Carina Bunschoten [b], Yusuf Rajabally [c], Luis Querol [d] on behalf of the participants of the 231st ENMC workshop

[a] Department of Neurology, Academic Medical Center, Amsterdam, The Netherlands
[b] Department of Neurology, Erasmus MC, Rotterdam, The Netherlands
[c] Neuromuscular Clinic, University Hospital of Birmingham, Birmingham, United Kingdom
[d] Hospital de la Santa Creu i Sant Pau, Universitat Autònoma de Barcelona, Barcelona, Spain

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1. Introduction

In May 2017, 24 people from 13 countries attended the 231st European Neuromuscular Center (ENMC) workshop in Naarden, The Netherlands, to provide an international standard for chronic inflammatory demyelinating polyradiculoneuropathy (CIDP) registries and biobanks. The group included researchers and clinical experts in inflammatory neuropathies, experts in neurophysiology and nerve pathology, three young researchers, and a patient representative from the patient organisation "Spierziekten Nederland" and GBS/CIDP Foundation International.

CIDP is a remarkably heterogeneous disorder including various atypical clinical phenotypes [1–5]. It is unclear whether the typical and atypical phenotypes share the same pathogenesis. Furthermore, despite various sets of diagnostic criteria [6–9], not all patients are yet identified, as there are reports of response to treatment in patients not fulfilling the current clinical and/or electrophysiological criteria [10]. Supportive diagnostic tests such as lumbar puncture, imaging and nerve biopsy can help in providing additional evidence for the diagnosis CIDP, but their diagnostic value has not been systematically assessed. Corticosteroids, intravenous immunoglobulin (IVIg) and plasma exchange are proven effective short-term treatments for CIDP, as summarised in Cochrane reviews [11–13]. Nevertheless, the choice of first-line treatment is primarily driven by patient's and physician's preferences as these treatments in general have comparable effects. Some patients show a monophasic and short disease course, while others have a relapsing-remitting or a chronic progressive course requiring regular maintenance treatment. During maintenance treatment, the optimal dose and interval of the chosen regimen is mainly by n = 1 experiments, since evidence-based strategies to optimize the treatment in individual patients have not been defined. There is a lack of biomarkers to monitor disease activity, which in combination with the highly variable clinical course makes it very hard to determine treatment duration and timing of withdrawal attempts.

2. Objectives of an international CIDP registry and aims of the ENMC workshop

Further research is needed to define the diagnostic clinical and electrophysiological boundaries of CIDP and its subtypes, and to define the role of biomarkers in supporting the diagnosis, monitoring disease activity and predicting response to treatment and outcome. Ideally, the choice of treatment should be based on a personalized profile including clinical, electrophysiological and biological characteristics that accurately predicts which treatment and regime will be most effective in a specific patient. More specifically, an international CIDP registry should provide information to fulfil the following objectives:

- Define variation of CIDP phenotypes and subtypes
- Improve diagnostic criteria
- Evaluate and improve clinimetrics
- Long-term treatment outcome and pharmacovigilance
- Develop a prediction model of treatment response and outcome
- Find biomarkers to support the diagnosis and monitor disease activity and treatment response
- Standardise the registry of patients and the collection of biomaterials to allow studies on pathogenesis and development of new treatment

* Corresponding author. Department of Neurology, Academic Medical Center, Meibergdreef 9, room H2-213, 1105 AZ Amsterdam, The Netherlands.
E-mail address: f.eftimov@amc.uva.nl (F. Eftimov).

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Several national registries and biobanks have been developed recently to enable systematic data collection in CIDP. However, even in large countries, these registries will not be able to include a sufficient number of patients to address the most important challenges described above. An international registry with large number of patients is needed to allow validation of prognostic models to predict outcome in individual patients with CIDP. During a debate on national databases at the Inflammatory Neuropathy Consortium (INC) meeting at Glasgow (June 2016), the need for international collaboration was once again emphasized, and the intention was laid out that centres could join existing database initiatives and that existing databases should be able to exchange data to a central database. The INC members agreed that an ENMC workshop would be the ideal setting to reach a consensus on the collection of a core set of clinical and diagnostic data and metadata, on the biomaterials, and on the infrastructure of databases and biobanks.

2.1. Aims of the ENMC workshop

2.1.1. Primary objectives

- Consensus on inclusion and exclusion criteria
- Core set of clinical data, diagnostic data and follow-up points including outcome measures
- An optional but recommended set of clinical data, diagnostic data and follow-up points
- A manual of operations for the collection of biomaterials

2.1.2. Secondary objectives

- A metadata dictionary
- Agreement on type of database(s)
- A timeline of merging data from existing databases
- Agreement on the infrastructure of coordinating centres
- Agreement on the governance of this initiative
- Proposals on ownership, publications, data sharing and biomaterial sharing

3. Preparations of workshop

Prior to the workshop coordinators of current CIDP registries were asked to fill in a questionnaire providing details on infrastructure, governance, inclusion and exclusion criteria, and collected clinical and diagnostic data. Details on collected biomaterials including storage conditions were noted. The questionnaires included details on used databases, software and possibilities to share the data.

4. Clinical data

4.1. Overview of clinical data from current registries

After a short introduction on the objectives of CIDP registries, representatives of five currently running registries provided a brief overview of their registries. More details on selection of patients, collected clinical data during baseline and follow-up, time points of follow-up were provided by Filip Eftimov in a comparison matrix of eight current registries (Italy, The Netherlands, Spain, France, Germany/Norway/India, Japan, Serbia/Montenegro and Belgium). Most registries were national and included CIDP patients only. All registries use the EFNS/PNS criteria for CIDP [6], but many allow inclusion of patients with suspected CIDP. The eight registries altogether have included over 1300 CIDP patients, with the majority being prevalent cases. Carina Bunschoten and Eduardo Nobile-Orazio provided an in-depth comparison between the Dutch pilot registry (International CIDP Outcome Study or ICOS) and the Italian registry, illustrating the similarities between the two registries. Furthermore, they also suggested a minimal baseline clinical data set.

The registries have different levels of complexity in terms of extensiveness of clinical data, diagnostic data entered at baseline and follow-up, and the collection of biomaterials. The Dutch, Italian and Japanese registries were considered the most extensive, being able to address all objectives mentioned above. However, it was recognized that these registries would be too burdensome for all eligible centres, as they require an extensive infrastructure, especially when considering fixed follow-up visits and biomaterial collection at each visit. In this report we will focus on the core data that can be collected by all centres (level 1 complexity). This core data will enable to address the following objectives:

1) Define variation of CIDP phenotypes and subtypes;
2) Improve diagnostic criteria;
3) Define the long-term treatment outcome;
4) Develop a prediction model of treatment response and outcome; and
5) Allow studies on pathogenesis based on collected biomaterials at baseline.

In addition, suggestions were made to harmonize data collection of more complex registries (level 2 complexity), that could address specific objectives such as risk factors for development of CIDP, improving clinimetrics, finding biomarkers of disease activity and pharmacovigilance of CIDP treatments.

4.2. Consensus on minimal baseline clinical data

At baseline, most registries include questions on symptoms and details from neurological examination to allow adequate description of the clinical phenotype. It was debated that the distinction between these phenotypes is more or less arbitrary and it is not yet clear whether making of this distinction is clinically important. Sensitivity of the EFNS/PNS criteria was generally regarded as suboptimal to detect all inflammatory neuropathies responding to treatment, especially those with pure sensory involvement. Therefore a consensus was reached that a CIDP registry should include all patients with the clinical suspicion of CIDP. The presence of detailed baseline data is needed to allow detailed clinical and electrophysiologal phenotyping of these patients to provide a better description of the CIDP boundaries but also to improve diagnostic criteria. It was also concluded that primary focus should be on CIDP, but inclusion of other chronic inflammatory neuropathies in the future should be considered after reaching a consensus on the infrastructure of the global registry. Registries should

include questions on which diagnoses were considered and/or excluded, following the recommendations of the EFNS/PNS guideline.

Further, in-depth comparison on how questions and answer options are formulated is needed to further harmonize protocols and to improve data comparison between registries. Summary of mandatory core baseline data on history and symptoms is provided in Table 1. Some of the more complex registries (level 2) will also include questionnaires to address possible association with developing CIDP.

4.3. Consensus on outcome measures at baseline and follow-up visits

Ingemar Merkies provided an update on outcome measures in CIDP [14]. To minimise burden of extensive follow-up visits, he suggested choosing one or two measures representing each outcome level of assessment, in essence at the impairment, activity and participation, and quality of life. Grip strength is generally considered as the most responsive outcome measure and should be used with preference given to the handheld dynamometer Martin Vigorimeter as the preference choice by CIDP patients. It was also recognized that in some patients (for example patients with gait ataxia as dominant symptom) grip strength might not be the most informative outcome measure. Therefore it was concluded that in addition to grip strength, treating physician should chose an impairment scale considered relevant for the individual patient. At activity and participation level, he suggested including the inflammatory Rasch Overall Disability scale (I-RODS) and the INCAT disability scale, the latter based on its use in various international trials as suggested by regulatory agencies. The EuroQol is a short questionnaire to measure quality of life and is suitable to use as health outcome. Finally, it was discussed to which level other patient-reported outcome measures (PROMs) should be used. As fatigue is a frequent complaint of CIDP patients, it was suggested that a (Rasch-built) fatigue severity scale (FSS) should be included. The minimal outcome measures used at baseline and follow-up visits are summarised in Table 1 (level 1).

More extensive registry protocols will include different impairment outcome measures and some already include more PROMs (level 2). This will provide important data to assess and improve the clinimetric value of existing outcome measures, and can help in the development of new outcome measures.

4.4. Consensus on minimal follow-up visits

Complex registries have follow-up visits at fixed intervals, with extra visits in case of a newly diagnosed patient, an unstable disease course or deterioration. It was also argued that this could prove difficult for all participating centres in which some patients are seen only occasionally due to large travel distances. Alternatively, some form of follow-up was judged necessary for various reasons, especially for verifying the diagnosis of CIDP. Patricia Blomkwist pointed out that long-term follow-up is very important to patients with a chronic disease and registries should address this. Several registries prespecified a minimum follow-up of two years, but some also regarded two years as too short.

Follow-up visits are therefore recommended for a minimum of 2 years and preferably as long as the disease is active. Visits may be scheduled at clinician's discretion, based on disease activity and health care infrastructure. Complex registries coordinators indicated that they would continue to use fixed intervals and additional visits if necessary that will provide more precise data on outcome and biomarkers of disease activity (level 2).

In addition to the outcome measures suggested above, follow-up visits should assess whether diagnosis has been changed and provide data on changes in treatment including tapering and/or withdrawal of treatment (level 1). Standardised questionnaire on adverse events of treatments could be used for pharmacovigilance (level 2).

Table 1
Core clinical data at baseline and follow-up.

	Level 1 complexity	Level 2 complexity (in addition to level 1)
Inclusion of patients	Clinical suspicion of CIDP	
Baseline data	- Epidemiological data - Onset and duration of symptoms - Phenotype - Treatment - Neurological examination	Questionnaires on associations
Outcome measures (baseline and follow-up)	- I-RODS - INCAT disability scale - Grip strength - EuroQol - (R)-FSS - Patient specific impairment measure(s) (at discretion of physician)	- MRC-SS - INCAT-SS - Numeric pain intensity rating scale
Follow-up visits	At clinician's discretion, minimal follow-up of 2 years recommended	Fixed visits and extra visits dependent on disease course
Follow-up data	Treatment changes	Registration of adverse events

Abbreviations: I-RODS = Inflammatory Rasch-built Overall Disability Scale; INCAT-SS = Inflammatory Neuropathy Cause and Treatment Sensory sum score; R-FSS = Rasch-built Fatigue Severity Scale; MRC-SS = Medical Research Council sum score.

5. Diagnostic data

5.1. Introduction to diagnostic tools in CIDP

Peter Van den Bergh provided an overview of the electrophysiological EFNS/PNS criteria for CIDP that have the highest diagnostic accuracy for the diagnosis of CIDP. Nevertheless, some patients with CIDP are not identified with these criteria while others are misdiagnosed. Some electrophysiological features could be used as predictor of treatment response, of which signs of extensive axonal damage is probably the most reliable predictor for lack of treatment response. Alternatively, the value of nerve conduction studies (NCS) as outcome measure during follow-up was considered of limited value by most participants and not practical for registries. Van den Bergh also illustrated that standardisation of NCS protocols remains an important problem. In some recent randomized controlled trials, tested nerves and stimulation sites were standardised, but it was questioned whether this is feasible for a registry in which laboratories of participating centres have different protocols and NCS are not routinely repeated.

Antonino Uncini followed by explaining how difficult it is to combine data from NCS studies in a single registry, as data cannot be transferred from NCS software to other databases. Manual entry of each value is currently needed which is extremely time consuming and prone to mistakes in data entry.

Stephan Goedee provided encouraging data on the role of ultrasound in the diagnosis of CIDP, which is not yet part of the diagnostic CIDP guideline. He also illustrated the varying results of the diagnostic value of MRI in supporting the diagnosis CIDP and suggested to consider including ultrasound as part of the diagnostic criteria for CIDP in the future.

Finally, Jean-Michel Vallat explained that nerve biopsy could be very valuable in patients not meeting the current diagnostic criteria for CIDP. One of the challenges of including nerve biopsy in a registry is the lack of standardised protocols for preservation and examination of nerve tissue. There are several techniques that can be used to study nerve pathology, and it was suggested that paraffin and epon embedding (semi-thin sections) are at least required to study nerve pathology. For the description of the pathologic abnormalities he suggested a qualitative and where possible a semi-quantitative (categorical) approach to describe 1) presence of inflammatory cells; 2) lesions of myelinated fibres; 3) lesions of unmyelinated fibres and 4) lesions of other types.

5.2. Overview of diagnostic data from current registries

After the introduction of the different diagnostic techniques, Yusuf Rajabally (YR) provided a comparison of the eight registries on diagnostic data. Diagnostic data was used in six registries, with variable number of diagnostic modalities being used. NCS studies and CSF results were collected in most registries. In four registries NCS protocol was prespecified but only in the Japanese registry a standardised NCS protocol was mandatory. It was concluded that there was considerable heterogeneity in NCS practice and data collection among countries with CIDP registries. YR emphasized that there are many practical issues that should be addressed prior to comparing data from NCS studies, such as standardising distal distances, definition of compound muscle action potential (CMAP) amplitudes and duration and body temperature. Another challenge is the upload of data into database as previously mentioned by Uncini.

5.3. Consensus/recommendations on diagnostic data

There was a consensus that meeting NCS criteria should be mentioned and if so, whether definite, probable or possible criteria were also fulfilled. A minimal NCS protocol was recommended by YR based on the neurophysiological criteria of the EFNS/PNS guideline. Motor nerve examination should include at least the unilateral forearm part of the median and ulnar nerve and the foreleg part of the peroneal and tibial nerve. Parameters should include a CMAP, distal motor latency, distal CMAP duration, mean conduction velocity, conduction block (CB) and temporal dispersion (TD) and F-waves. Sensory nerve examination should include at least two nerves of the upper limb (median, ulnar, or radial) and one lower limb (sural), registering the sensory nerve action potential (SNAP) amplitude and sensory nerve conduction velocity. It was also recognized that in most cases more extensive protocols are needed to rule out a demyelinating neuropathy but that in some cases limited studies are sufficient to confirm a demyelinating neuropathy. As NCS protocols and limits of normal values for each parameter vary throughout laboratories, a standardised protocol is needed that includes guidelines on temperature and distal distances, and use of normative values (normalization of data in percentages of upper and lower limits of normal and ratios CMAP/SNAP and CB/TD).

Upload of raw NCS data into any databases directly from NCS software is currently impossible. Steps to enable transfer of data will be undertaken, first by contacting EMG manufacturers.

Collection of other diagnostic data is needed to improve diagnostic criteria and develop prognostic modelling of treatment outcome. Except for cerebrospinal fluid results, uploading of raw data of MRI, ultrasound imaging and biopsies is challenging, as data files are very large. Therefore, it was considered sufficient to enter CSF results and information on whether other diagnostics were performed and whether these were normal or not. Source data from imaging and biopsies can be retrieved in a later stage if judged necessary.

6. Biomaterials

6.1. Introduction and overview of collected biomaterials

Biomaterials of interest in CIDP are serum, DNA, RNA, peripheral blood mononuclear cells (PBMC), CSF, nerve and skin biopsies. Kathrin Doppler presented the advantages and disadvantages of central storage versus storage at each participating centre, as these are the two main infrastructures currently used in registries. Ivana Basta used an example of their collection of biomaterials on limb girdle muscular dystrophies to present the infrastructural possibilities and challenges in middle-income countries. In these countries additional funding is often needed for storage and shipment of biomaterials.

Luis Querol (LQ) provided an overview on the biomaterials collected in the registries. At baseline, serum was collected in 5 registries, DNA in 3 registries, with additional materials collected in the Japanese registry and selected ICOS centres only. Registries used both central storage and storage at participating centres. Finally, LQ proposed a modular view to collection of materials, allowing centres with special scientific interest to collect biomaterials as judged necessary.

6.2. Consensus on collection of biomaterials

A registry that includes sampling at each visit was regarded as not feasible for most centres, as this requires a complex infrastructure. Serum at baseline was considered a minimal acquirement. Collection of DNA is largely dependent on local legislation/regulation, and mandatory collection was considered too complex. Collection of other materials at baseline will be only performed by centres with specific interest in biomarkers of disease activity and pathogenesis of CIDP. Storage of materials at participating centres was preferred above central collection for various reasons including feasibility in terms of costs, legal issues (especially on DNA collection), and autonomy of participating centres to follow different study protocols. The need of standardised protocols for specimen collection of serum, CSF and biopsies was again emphasized.

7. Database, governance, legal considerations and funding

7.1. Overview of current databases

Max Adrichem and Luis Querol gave an introduction on possible registry infrastructures (network topologies), explaining the advantages and disadvantages of all these structures. In this overview, software of databases used in the current registries was compared illustrating how much effort has already been put in different databases. Different registries used heterogeneous databases, but this is less important as long as data can be exported and combined with data from other databases. Creating a common data dictionary is crucial to combine data already collected and to harmonize databases in the feature. Harmonizing case report forms and data entry fields at question/answer level are necessary to enable a common data dictionary. Stephen Reddel introduced MSbase, a large global database that encompasses not only multiple sclerosis but also other neuroimmunological conditions and suggested incorporation of CIDP registries into MSbase. Important advantages would be the established infrastructure of MSbase and comparison of CIDP to other neuroimmunological disorders. Alternatively, MSbase is less suitable for more complex registries. Also, MSbase is governed largely by people not involved in CIDP research and this was considered a major disadvantage.

7.2. Patient participation, legal considerations and funding

Patricia Blomkwist reported on the role of the GBS/CIDP Foundation in other registries such as the International Guillain–Barre Outcome Study (IGOS) and emphasized how important such global initiatives are to patient groups. David Cornblath and Bart Jacobs gave examples of how funding can be secured, including grant proposals to the GBS/CIDP Foundation, private parties and pharmaceutical companies. Many IVIg manufacturers have already provided funding to current registries such as CSL Behring to ICOS, Kedrion to the Italian registry and Grifols to the Spanish registry. In a more global initiative, pharmaceutical companies are considered as potential partners as these registries can provide data on long-term treatment efficacy and pharmacovigilance and improve outcome measures for clinical trials. Finally, Michael Lunn summarised the upcoming changes in the EU directive on data sharing. Increasingly, data sharing has become more complex as there is a narrow balance between privacy regulation and increasing need for collaboration and big data. In addition, a global registry should take into consideration the different legislation and regulations of different countries (i.e. USA versus the European Union). Legislation and regulations around data appears to be a very dynamic field, and a new EU directive providing more clarity on many issues is expected in 2018. Given the complexity of governance of a global database, close collaboration with data protection officers will be needed.

7.3. Consensus on database

The discussion on databases included the governance and legal considerations, as these are greatly dependent of each other. The main advantage of having a central database is more uniformity, sharing of common objectives in the future but it comes at a cost of more complex governance. Most participants therefore preferred a decentralized infrastructure in which centres use the separate databases that share data with a central database. Local databases can remain adjustable to provide the local needs of participating centres and allow centres to continue ongoing national studies that are already imbedded in their infrastructure. A decentralized infrastructure requires that registry protocols are harmonized and that a uniform data dictionary will be developed to ensure that meaning, relationships to other data, origin, usage, and format of data-fields are comparable.

The central database can be used to combine data between two or more registry databases. New centres that want to participate can then join existing local registry databases or enter data directly into the central database. All centres remain owner of their data and can withdraw these data from the central registry. A set of requirements was set for a central database that is summarised in Table 2. As the Inflammatory Neuropathy Consortium was considered as one of the major driving force behind this initiative, the name INCbase was suggested for the central database.

7.4. Consensus on governance and funding

An INCbase Steering Committee (SC) that can govern INCbase will be established. However, it was decided to install an INCbase task force first that can elaborate on the newly formulated objectives before setting up an SC. This task force has to reach consensus on some open items and has to move forward many other tasks that lay ahead that require specific know-how of the currently running registries and databases

Table 2
Central database requirements.

Central database requirements
Versatile, can accommodate data from both simple and complex databases/follow-up
Data from existing registries data can be transferred (after adapting field definitions/data dictionary)
Allows uploads/downloads and erasure of personal data according to current and future legislation and fair guide principles (ownership and sharing)
Allows extraction of data at centre level
Graphical interface
Allows upload of digital PROMS questionnaires
Free text possible
Possible expansion to other neuropathies in future

infrastructure, biobank protocols, legislation and funding. Where INCbase will be centred will depend on these factors, and this was not addressed at the workshop.

Ongoing funding is one of the crucial requirements for this project. Funding will be needed for the development and management of the central INCbase database, management of databases and biobanks of current registries, monitoring if required by local legislation and specific projects to analyse data or biomaterials. The task force will submit grant proposals for the central database to pharmaceutical companies and the GBS/CIDP Foundation. The registry coordinators are responsible for funding of currently running registries. Local sites will be assisted in the future by the SC to obtain funding for biobanks and specific research questions.

8. Further steps and timeline

Future steps can be divided into two major categories:

1) Harmonize current registry protocols;
2) Develop INCbase as a central database that interacts with current registries.

The INCbase task force will consist of the following ENMC participants: Eftimov (chair first objective), Querol (chair second objective), Allen, Antoine, Basta, Doppler, Lehmann, Lunn, Jacobs, Nobile-Orazio, Rajabally and Reddel. In addition Professor Sobue from Japan agreed to participate in the task force.

For the first objective there is a need of a detailed comparison of current registries study protocols, case reports forms and data entry fields. The task force will advise on possible adjustment of current protocols, set a minimal core set for baseline data and create standardised protocols for NCS studies and data collection, serum, CSF, nerve and skin biopsy collections. The possibilities of automatic data transfer from NCS software to other databases will be explored by contacting NCS hardware and software companies.

For the second objective of choosing a new central registry we will first request dummy log in accounts to existing databases to compare advantages and disadvantages. Potential databases will be screened whether they fulfil the database requirements summarised in Table 2. Fields required in the central database need to be defined, allowing also input from more complex protocols. Database companies and data managers of existing registries will be contacted to explore the possibilities of creating a common data dictionary. Similarly, we will contact data protection officers in different countries (EU/UK/USA/Japan) and coordinators of other global databases to anticipate expected changes in legislation. Pharmaceutical companies will be contacted for funding of INCbase.

9. Timeline

- July 2017: comparison of registries' data fields and agreement on minimal core data set for central database
- September 2017:
  1) proposal for adjustments of current protocols; and
  2) workplan for standardisation of NCS data and samples collection
- January 2018: secure funding for INCbase; decision on INCbase database; finalize data dictionary; combine data from existing registries.
- May 2018: finalize INCbase; enter data of first new patient.

10. Summary

Eight currently ongoing international CIDP registries were compared to assess infrastructure and collected clinical data, diagnostic data and biomaterials to enhance future research and improve standards of care in CIDP.

Consensus was reached on:

- Inclusion criteria: clinical suspicion of CIDP; exclusion criteria: other diagnoses.
- The need of extensive baseline clinical and diagnostic data in defining phenotypes but the minimal core of clinical data is yet to be defined.
- Flexible follow-up visits with preferably at least a 2-year follow-up. Minimal outcomes during follow-up: a) grip strength, fatigue, disability (INCAT and iRODS), quality of life (EuroQol) in all participants and b) impairment outcome measures based on individual patient characteristic at physicians discretion.
- A minimal protocol for nerve conduction study was suggested.
- Collection of biomaterials (serum, CSF, nerve biopsy) should be according to standardised protocols, with at least serum collection at baseline. Biomaterials are stored in participating centres or coordinating centres.
- Infrastructure: a central database (INCbase) will be developed in which data from existing database can be uploaded. A set of requirements for INCbase was defined. Current registries and databases continue to exist.
- All centres remain owner of data and biomaterials and can withdraw data from INCbase.

Proposed plans:

- Task force to harmonize the current registry protocols and develop INCbase as a central database.
- The task force has proposed a timeline for the development and finalization of this registry with a plan to include first new CIDP patient into INCbase by May 2018.

11. Workshop participants

- Max E. Adrichem, Amsterdam, The Netherlands
- Jeffrey Allen, Minnesota, United States of America
- Jean-Cristophe Antoine, Saint-Etienne, France
- Ivana Basta, Belgrade, Serbia
- Peter Van den Bergh, Brussels, Belgium
- Patricia Blomkwist-Markens, Amsterdam, The Netherlands (GBS/CIDP Foundation International)
- Alexandra Breukel [ENMC], Naarden, The Netherlands
- Carina Bunschoten, Rotterdam, The Netherlands
- David Cornblath, Baltimore, United States of America
- Kathrin Doppler, Wurzburg, Germany
- Filip Eftimov, Amsterdam, The Netherlands
- Stephan Goedee, Utrecht, The Netherlands
- Robert Hadden, London, United Kingdom
- Thomas Harbo, Aarhus, Denmark
- Fu Liong Hiew, Kuala Lumpur, Malaysia
- Bart C. Jacobs, Rotterdam, The Netherlands
- Helmar Lehmann, Cologne, Germany
- Michael P. Lunn, London, United Kingdom
- Ingemar S.J. Merkies, Curaçao, Curaçao
- Eduardo Nobile-Orazio, Milan, Italy
- Luis Querol, Barcelona, Spain
- Yusuf Rajabally, Birmingham, United Kingdom
- Stephen Reddel, Sydney, Australia
- Jean-Michel Vallat, Limoges, France
- Antonino Uncini, Chieti, Italy

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