

**Annual report French Brain Council (FBC) actions**

**2017-April 2018**

**I) New members of FBC.**

Continuous andsignificant efforts were made to enlarge the number of FBC members in particular by welcoming Foundations and Associations representing patients at the national level.

Among these new members the Fédération pour la Recherche sur Cerveau (FRC) [http://www.frcneurodon.org](http://www.frcneurodon.org/) is of utmost importance for increasing the FBC visibility.

**The FRC** is a non profit association gathering six Patients’ Associations or Foundations representing 6.000.000 patients:

1. ARSLA Association pour la recherche sur la SLA/ [https://www.arsla.org](https://www.arsla.org/) ,
2. ARSEP Fondation pour la Recherche sur la Sclérose en plaques [https://www.arsep.org](https://www.arsep.org/),
3. FFRE Fondation Française pour la Recherche sur l’Epilepsie [http://www.fondation-epilepsie.fr](http://www.fondation-epilepsie.fr/),
4. France Parkinson [http://www.franceparkinson.fr](http://www.franceparkinson.fr/) ,
5. UNAFAM Union Nationale des Familles et amis des personnes maladies et/ou handicapées psychiques [http://www.unafam.org](http://www.unafam.org/)
6. AMADYS Association des malades atteints de dystonie [https://amadys.fr](https://amadys.fr/)

The FRC is supporting public dissemination of knowledge and research on brain diseases in France. It supports the Brain Awareness Week at the national level. The 20th edition of Brain Awareness Week was organized on March 12th -18th 2018 in more than 40 sites over the national territory.

**The French Clinical Research Infrastructure Network** F-CRIN [[http://www.fcrin.org](http://www.fcrin.org/)] is an organization controlled by the National Research Agency in charge of promoting French clinical research at European and International level, supporting multi-centric trials coordinated by French clinical teams and innovative proof of concept projects.

**Congrès Français de Psychiatrie** CFP[https://www.congresfrancaispsychiatrie.org](https://www.congresfrancaispsychiatrie.org/). This organization gathering more than 90 partner associations of psychiatrists and patients is in charge of the annual French Congress of Psychiatry. During the last edition of this Congress, which took place in Lyon on November 29th –December 2nd, Frédéric Rouillon, vice-President of FBC presented the structure and aims of the French brain Council and François Mauguière as President of the FBC delivered the opening conference on the theme: ‘Physical Pain, Social Pain and Empathy to others share a common representation in the human brain’. Participation of the FBC in this event is critical to connect Psychiatry-Neurology and Neuroscience in France. The next CFP will take place in Nantes on November 28th- December 1st 2018. The FBC is candidate to organize a session.

**ICM** Institut du Cerveau et de la Moelle épinière <https://icm-institute.org/fr/> . The ICM is the largest French Institute devoted to basic and clinical research in Neuroscience.

**II) FBC coordination with the Institut Thématique Multi-Organismes ITMO** Neuroscience, Sciences Cognitives, Neurologie, Psychiatry [[https://itneuro.aviesan.fr](https://itneuro.aviesan.fr/) ]

The ITMO is one of the institutes of the Alliance Nationale pour les sciences de la vie et de la Santé (Aviesan: [https://aviesan.fr](https://aviesan.fr/) ) which gather all national organisms involved in research and University hospitals . Mohamed Jaber as FBC secretary and François Mauguière as FBC President had a meeting with ITMO representatives on December 2017 to present the organization and aims of the FBC and to evaluate the possibility of launching a National Brain Plan. The conclusion in this regard was rather disappointing based on the argument that more than 40 plans specific to various brain diseases are launched or under evaluation at the French Ministry of Health.

A positive issue was that François Mauguière was invited to participate in a national brainstorming on ‘Neurosciences in the next 20 years’, which took place in Lyon on February 12th and 13th 2018. The following topics were open to discussion:

1. Brain development, Plasticity and Repair
2. Ecological Neuroscience
3. Computational Neuroscience
4. Closed loop Neuroscience
5. Cognitive development
6. Connectome & cellular interactions
7. Social insertion of handicapped persons
8. Neuroscience & Pedagogy
9. Management of research and training
10. Social brain & social interactions
11. Innovative Neuro-imaging techniques
12. Ethics & Neuroscience
13. Neural ageing

The final report of this brainstorming will be presented at the Collège de France on September 28th 2018 and submitted to national authorities. This report should be translated in English and the FBC proposal is that François Mauguière will present this report at an EBC board meeting early in 2019.

**III)** **Coordination of a FBC session at the 2019 NeuroFrance Congress in Marseille May 22nd -24th** <https://www.neurosciences.asso.fr/V2/colloques/SN19/>

The NeuroFrance congress is organized once every two years by the French Neurosciences Association. It is the largest multidisciplinary meeting on Neurosciences in France.

The FBC has proposed to organize a whole session at the forthcoming NeuroFrance congress on : ‘The revival of Neuropsychiatry: a Neuro-scientific evidence’ *(see below Annex 1).*

**IV)** **Survey on the current state of care for patients suffering from brain diseases in France.**

Based on the questionnaire elaborated by the Belgium Brain Council members of the FBC task force have elaborated a survey of state of care for patients with Brain diseases. *(see below Annex 2).* This survey will be presented and discussed at the NBC Academy meeting in Lisbon on April 17th- 18th 2018.

**V) Recruitment of two experts of Alzheimer’ disease and related cognitive disorders in the FBC task Force.**

In February 2018 Profs. Florence Pasquier and Pierre Krolak Salmon have accepted to join the FBC task force. The 2018 composition of this task force is given in Annex 3.

The FBC is probably the only FBC with such a large panel of experts ready to contribute to EBC actions covering all fields of Brain disease. It is surprising and disappointing that for the past two years they have received no mission from EBC. This issue mentioned repeatedly at the EBC Board meeting will be tabled once more at the NBC Academy meeting in Lisbon.

 Lyon April 12 2018

 

 Prof. François Mauguière

 FBC President

**ANNEX 1**



**NeuroFrance 2019**

**Symposium Proposed by:**

**The French Brain Council**

**The revival of Neuropsychiatry: a Neuroscientific evidence.**

President François Mauguière (Lyon)

The French Brain Council [http://conseilfrancaisducerveau.org](http://conseilfrancaisducerveau.org/) was founded in 2016 by the French Societies of Neurosciences and Neurology and a College of Psychiatric associations in order to foster the links between Brain Research, Advances in Clinical Research on Brain Diseases and Societal issues raised by the development of innovative therapies. This Symposium tackles topics for which the borders between psychiatric and neurologic diseases are now blurred by our present knowledge of their pathophysiology based on the progress of Neurosciences.

This symposium covers the following domains:

* Neuroimmunology
* Behavior, Emotions and Cognition
* Neurological and Psychiatric diseases.



**Program**

**Jérôme Honnorat (Lyon)**

* Mechanisms of autoimmune encephalitis with psychiatric presentation

**Marion Leboyer (Paris)**

* Auto-Immune psychosis

**Philippe Damier (Nantes)**

* Behavioral disorders induced by antiparkinsonian treatment: a window onto the human dopamine system

**Richard Levy (Paris)**

* The scientific challenges of fronto-temporal lobar degeneration

**Francis Eustache (Caen)**

* Neuropsychology and neuroimaging of social cognition in neurological diseases

**ANNEX 2**



**Survey on the current state of care
for patients suffering from brain diseases in France**

**Contributors:**

Prof. Jean-Yves Delattre

Prof. Philip Gorwwood

Prof. Yves Dauvilliers

Prof. Emmanuel Haffen

Prof. Pierre Krolak-Salmon

Prof. Jean-Antoine Giraud

Prof. Marion Leboyer

Prof. Rançois Mauguière

|  |  |
| --- | --- |
| **Question** | **Answer** |
| In terms of prevention, diagnosis, treatment and rehabilitation of brain diseases, how would you evaluate the current state of affairs? | * Good quality of care in France for Neurological diseases
* Management of psychiatric diseases is underdeveloped. Little academic involvement. Organization through geographic sectors with variable and sometimes questionable quality of follow up. Insufficient follow-up of psycho-social and quality of life. Major disparities over the national territory.
* Under and late diagnosis of neurocognitive and sleep disorders, especially due to under detection in primary care
* Not enough emphasis on rehabilitation programs. Poor evidence regarding non pharmacological therapeutics, e.g. rehabilitation (cf Cochrane)
* Deficient screening and prevention programs for psychiatric diseases.
* Poor connection between Neurological and Psychiatric care.
 |
| Which disease entities are given priority and what does this entail? | * Stroke and neurodegenerative diseases benefit from dedicated national plans or structuration
* Alzheimer’s disease and related disorders (ADRD) are given priority because of increased prevalence despite slowing of incidence.
* Many psychiatric and neurological disorders are not sufficiently supported.
* The focus should be made on Schizophrenia, major Depression Disorders and suicide
* A national public health plan should be devoted to the study and evaluation of cognitive, attention and vigilance disorders in the general population and to implement actions to decrease the everyday risks due to these disorders.

 [...]  |
| What are the current trends in terms of improving care for patients with brain disorders? Which aspects are emphasized? | * Significant efforts are ongoing to improve healthcare pathways and ambulatory management with a strong incentive to reduce hospitalization (national policy being prepared).
* Reference centers on dedicated diseases (Parkinson) and rare neurologic diseases are pursued
* Emphasis should be focused on:
1. Enhancing diagnosis rates at earlier stages
2. Specific individualized diagnosis and care pathways
3. Post-diagnosis supports to optimize quality of life and provide secondary prevention dynamics
4. Access to advanced directives and to clinical trials
5. Patient-centred care (which means taking care of the patient opinion and participation) and personalized (one care for one patient).
6. Foster interaction between basic and clinical research particularly by increasing the number of MDs involved in national research teams (INSERM)
 |
| Has there been increased government spending for patients with brain diseases? If yes, how much (within the last 3 years)?  | * Specific projects are focused on neurodegenerative diseases (national plan) and reference centers, mainly rare neurological diseases.
* For ADRD in France, roughly 1.6 billion euros since 2007
* Otherwise, no increased spending particularly on psychiatric and addictive disorders except for the 3rd national plan on autism.
 |
| Are the different specialties (general practice, neurology and psychiatry) clearly demonstrating increasing collaboration in the care of patients with brain diseases? | * Communication and collaboration between psychiatry and neurology are weak but improve slowly with a few new units dedicated to behavioural disturbances (behavioural neuropsychiatry units) directed by both neurologists and psychiatrists.
* The number of multidisciplinary meetings is increasing but only in university hospitals.
* At the national level and at the European level a consensus statement has been published in 2018 on individualized diagnosis involving GP’s, neurologists, geriatricians, psychiatrists and other professionals. A French version, and a European version of the consensus are available.
 |
| Is the emphasis shifting towards the provision of care by General Practitioners, nurses or other trained assistants? | * No, and this is a major issue. We are very late in France for these new jobs involving specialized paramedical staffs playing a key role in patients’ management. On this issue, there is a discrepancy between official announcements and the situation on the ground.
* Primary care professionals take part in the elaboration of the current national plan on neurodegenerative diseases.
 |
| For the disease listed below: 1) How do patients access pharmaceuticals? 2) In the last three years, has access to new and innovative technologies and treatments improved? (MS, Alzheimer’s, Parkinson’s, depression, stroke, schizophrenia, TBI (traumatic brain injury). What has been achieved? Where are the gaps?  | * Access to innovative treatments and technologies have improved for Multiple sclerosis and Stroke. Main achievements in providing access to innovative treatments for MS and Stroke with a rather good equity around the country.
* No major change over the past three years for ADRD, Parkinson, Stroke and TBI
* The delay to access to Neuroimaging or Clinical Neurophysiology platforms is too long in many national territories.
* Symptomatic therapeutics for ADRD still reimbursed in France but with threat for cancellation of this measure. The major gap is to find a disease modifying drug and to specify which non pharmacological approaches are the most efficient in terms of quality of life and secondary prevention
* For psychiatric disorders (Major Depressive Disorders (MDD and schizophrenia) few changes. Some progress for early detection of schizophrenia, which improves its global outcome. Very few new psychotropic drugs for schizophrenia (as if), but some developments for MDD (ketamine, brexpiprazol…). More “serious games” (eCBT) should be developed, especially for minor depression. The level of reimbursement is getting smaller each time a product is proposed on the market.
 |
| Have solutions been implemented in terms of better coordination in the care of brain diseases? If yes, which disease entities does it refer to? We would be grateful for sending the implemented model  paths.   | * Poor because the culture of expert coordinating paramedical staff is very slow to develop in France, leading to rupture of healthcare pathways between hospital-general practitioner-rehabilitation-patients and home. Interesting ongoing experiences for ALS, epilepsy, Parkinson and a few other diseases.
* For ADRD health and medico-social networks are under dissemination in the country but the geographic coverage still needs major improvement. (cf Neurodegenerative plan on the site: [http://solidarites-sante.gouv.fr](http://solidarites-sante.gouv.fr/)
* Expert centers are being developed for schizophrenia, they could serve as platform for care, but this is rarely the case.
 |
| In your opinion, is care coordinated for patients with coexisting brain diseases? If so, how does this occur? | * Yes for ADRD comorbidities in some subspecialties (cf above) but it is not general practice. Experience shows that a coordinating person (trained paramedical staff) is mandatory but it remains quite difficult to train and hire these professionnals.
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| Does the public domain support non-commercial clinical trials for patients with brain diseases? Can you share information about trials of this type?  | * Yes, to some extent through the PHRC (programme hospitalier de recherche Clinique) which is quite selective. Otherwise, some philanthropic and patients associations help funding.
* For ADRD one national trial on detection in primary and one national trial on pharmacological symptomatic therapeutics are in preparation. Not enough trials on non-pharmacological approaches
 |
| What are the challenges in improving care for patients with brain diseases? | * Improving translational and clinical research.
* Fostering education of future MDs and PhDs focused on medical applications of innovative technologies, instrumentation, statistics, artificial intelligence…
* Identification of biological markers for diagnosis and evaluation of the response to treatments.
* Better structuring of coordinated healthcare pathways i.e: Integrated and personalized diagnosis and care pathways.
* Improving rehabilitation programs
* Place the focus on psychiatry, which is clearly the “poor parent” of our disciplines with only 2% of biomedical national research budget devoted to psychiatry.
* Stigmatization, new approaches, using new technics, changing paradigms
 |
| How does the government support care for patients with brain diseases?  | * Through reference centers on frequent (eg Parkinson) or rare neurological diseases (eg Gilles de la Tourette). These reference centers are a real progress in our country to improve patients’ care. Management of stroke patients is well organized. Unfortunately, psychiatry is not thoroughly involved in these programs.
* 4 national plans were dedicated to ADRD (3) and neurodegenerative diseases (the current one)
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| In the past few years, has the healthcare system made the care of patients with brain diseases a priority? If so, are there any public documents, documenting this or any other examples? If yes, we would be grateful for sending/ sharing | * A real effort has been made through dedicated plans (neurodegenerative diseases), national structuration (stroke), reference centers (Parkinson,..) and centers for rare diseases which have been rather successful. see : [http://solidarites-sante.gouv.fr](http://solidarites-sante.gouv.fr/)
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**ANNEX 3**

**FBC Task Force 2018**

**Neuro-oncology**

* Prof. **Jérôme Honnorat**
* Prof. **François Ducray**

**Multiple Sclerosis**

* Prof. **Michel Clanet**
* Prof. **Sandra Vukusic**

**Epilepsy**

* Dr. **Marie-Christine Picot**
* Prof. **Sylvain Rheims**

**Parkinson’s disease and Movement Disorders**

* Prof. **Marie Vidailhet**
* Prof. **Philippe Damier**

**Psychiatry**

* Prof. **Marion Leboyer**
* Prof. **Pierre Michel Llorca**
* Prof. **Philippe Courtet**
* Prof. **Emmanuel Haffen**
* Prof. **Manuel Bouvard**
* Prof. **Richard Delorme**
* Prof. **Philip Gorwood**
* Prof. **Luc Mallet**

**Stroke**

* Prof. **Yannick Béjot**

**Public Health & Medico-Economy**

* Prof. **Anne-Marie Schott**
* Prof. **Isabelle Durand-Zaleski**

**Neuropathies**

* Dr. **Jean-Marc Léger**

**Alzheimer & cognitive disorders**

* Prof. **Florence Pasquier**
* Prof. **Pierre Krolak Salmon**