

# A twinning action for improving the medical care of haemophiliac patients in the West Algerian region

Algeria counts 33 millions inhabitants, about 1200 haemophiliacs, and one recognised haemophilia centre in Algiers. Networking for medical care and proximity treatment were the main recommendations of a consensus conference, organised in 2002, in Algiers, under the auspices of the Algerian Health Ministry to alleviate the difficulties in care, diagnosis, follow-up and treatment availability for haemophiliacs. In 2005, a medical twinning started between the Strasbourg CRTH and the Haematology departments of Oran and Sidi-Bel-Abbès hospitals to improve both the existing medical care and the West network organisation. Within this framework, the following activities were organised:

(a) Four scientific meetings (state of medical care and regional patients' committee, prophylaxis, orthopaedics, inhibitors) at the university hospitals of Oran, Sidi-Bel-Abbès and Tlemcen. (b) Training courses (haematologists, orthopaedists) at Strasbourg hospital; (c) Multidisciplinary consultations for medication and orthopaedic therapeutic evaluation in Oran and Sidi-Bel-Abbès hospitals. In addition, the World Federation of Haemophilia organised a meeting (Algiers, 03/2007) to support the Algerian National Haemophilia Association and regional committees.

Links were then established between the French and Algerian associations of haemophilia. The existing twinning enabled the Strasbourg CRTH to co-operate in the ongoing national training programme for haemophilia care which started in 2007 under the auspices of the Algerian Health Ministry, coordinated by a national medical committee and supported by the Novo Nordisk Foundation.

These activities aimed to organise haemophilia care by setting-up: (1) regional haemophilia centres ensuring diagnosis, care and follow-up and (2) proximity treatment in accordance with the national health policy.



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## Foreword: Haemophilia care in Algeria

- The first haemophilia care was organised in the beginning of 60s at the Algiers Mustapha Bacha Hospital. Diagnosis and treatment were progressively taken in charge by most university hospitals
- 1989 (11/09): agreement of the Algerian Haemophiliacs Association
- 1996 : Opening of the 1st Haemophilia Centre at the Algier University Hospital Béni-Messous for the Algerian centre region haemophiliacs care
- 2000 : First national epidemiology study under the auspices of the Health Ministry. 976 haemophiliacs = 3.25/100 000 inhabitants (expected number: 1500 – 3000)
- 2006 updated: 1128 haemophiliacs = 3.76/100 000 inhabitants  
Distribution per region: Centre: 36%; East: 24%; West: 24%; South-West: 3%. South-East: 2%.
- 2002 : Consensus Conference on therapeutic care and care networking.
- 2005 : Health Minister Decree (22/11/2005 n° 007/SPMIN/MSPRH/05) on pharmaceutical products management in public health hospitals

## Introduction: the West region before the twinning

- **Diagnosis:** As the West region hospitals could hardly diagnose haemophilia and Willebrand disease (lack of automates and reactivities), most haemophiliacs and Willebrand patients were obliged to go to Algier for diagnosis
- **West Algerian Haemophiliac network;** Medical and associative willingness to set up a network in line with to the Consensus Conference recommendations:
  - First medical meeting (Oran, November 2005) in the framework of the twinning, the existing West medical network was presented by the co-ordinator Pr H. TOUHAMI, grouping 14 wilayas health sectors around the 4 haemophilia regional hospitals of Oran, Sidi Bel Abbès, Tlemcen and Béchar
  - Associative meeting (Ghazaouet (Tlemcen), december 2005), emphasized the need of networking :
- **Medical care:** 230 haemophiliacs were identified among 6 842 663 inhabitants (prevalence: 3.36 /100 000 inhabitants), 79 of them (adults) being treated at the Oran University Hospital and 31 (children) at the Canastel Oran paediatrics Hospital.
- **The haemophiliac associative movement:** several associations (Oran, Mascara, Tlemcen, Béchar) existed and the remaining one, Ghazaouet, was the most active and organised an annual seminar on haemophilia. Demotivation of haemophiliacs linked to the chronic lack of medicines availability .

## Twinning Activity (2006-2008)

### First medical and associative meeting

#### Medical meeting : Sidi Bel Abbès (09/2006)

- **The prospective cohort of haemophiliacs of the West region :** 287 haemophiliacs
  - Oran and its area (Mostaganem, Chlef, Ain Defka, Tissemsilt) : 114
  - 89 of them are identified in the Oran University Hospital.
  - Sidi Bel Abbès University Hospital and its area (Mascara, Saïda, Tiaret, El Bayad) : 91
  - Tlemcen University Hospital and its area (Ain Temouchent, Ghazaouet, Nedroma, Beni-Saf, Maghnia, Naama) : 48
  - Béchar Hospital and its area (Tindouf, El Bayadh, Adrar) : 34
- **Medical care:** Despite an adequate structure for haemophiliacs (medical, surgical, biological)
  - Difficulties in availability of medicines linked to unexpected emergency arrivals of haemophiliacs from other wilayas.
  - Numerous problems as regards the diagnosis (lack of reactivities), follow-up (distance, low socio-economic level) or in case of emergency and availability of treatments
- **The twinning proposed to contribute to:**
  - the care organisation through a regional networking between the 3 University Hospitals (Oran, Sidi Bel Abbès, Tlemcen) thus constituting the West Regional Centre.
  - set up a proximity treatment (with the setting up of the self-treatment practice) to compensate difficulties linked to too long distances to reach neighbouring hospitals and health centres in each wilaya.
  - the setting up of diagnosis screening and confirmation, follow up and major surgery (orthopaedic...) in University Hospitals.

#### Associative meeting : Sidi Bel Abbès (09/2006)

- Mr J.M. BOUCHEZ, General Secretary of the French Association of Haemophiliacs participated in the meeting with representatives of different regional associations and the Algerian National Association.
- Pr H. TOUHAMI proposed to organise soon a general constitutive assembly in Ghazaouet aiming to set up the regional association according to the will of the founding members.
- A collective enthusiasm emerged from this meeting, in particular as regards the willingness to build together an associative movement which could help everybody.

### Thematic medical meetings

#### Orthopaedic aspects of haemophilia : University Hospital of Tlemcen (03/2007)

- Dr A. FARADJI, Pr J. SIBILLIA, rheumatologist, Dr J. DURCKEL, radiologist and N. EL RIFAI, physiotherapist (Strasbourg University Hospital), shared their experience with Algerian medical doctors.
- Pr H. TOUHAMI presented the medical care organization of the West region network and the updated haemophilic cohort : 327 among them 117 at Oran University Hospital.
- Prof Z. ZOUAOUI mentioned the medical and associative progress made:
  - set up of the West region haemophiliacs register since the regional meeting in Ghazaouet (12/ 2006);
  - set up of the Haemophilic association of Sidi Bel Abbès with the agreement of the Wilaya.
  - training of biologists, orthopaedists, physiotherapists, etc... with the twinning project, and national plan contributions;
  - Future setting up of haemophilic self-treatment
- Prof. J. SIBILLIA: *"During this meeting, we shared our knowledge, the issue of our experience, but now we should start real training activity. Through networking, I am sure that the haemophilia care will progress in a warm and brotherly spirit thus conveying our strong links"*.



#### Inhibitor aspects of haemophilia : University Hospital of Oran (06/2007)

- Dr A. FARADJI, Dr C. COSTA (medical genetician, Creteil Hospital, Paris) and Dr T. LAMBERT (Haemophilic Centre of the Kremlin Bicêtre Hospital, Paris) shared their experience with the West region haematologists.
- Update of the data register of the West Algerian haemophilia network: Oran 110, SidiBelAbbès 78, Tlemcen 54.
- Dr COSTA : *"I was charmed by the kindness and simplicity of all people I met during this short stay. I was welcomed and looked after in an exemplary manner and with a real professionalism. I was struck by the difficulties encountered by the medical staff in all fields, in particular in haemophilia. I admired the way medical doctors and nurses care for their patients while knowing what they could do but cannot due to the lack of means. Your work is a real support and their hope for the future is very encouraging."*



#### Prophylaxis aspects of haemophilia : University Hospital of SBA (09/2007)

- Dr A. FARADJI, Profs H. CHAMBOST and J. GOUDEMAND (Haemophilic Centers of Marseille University Hospital and of Lille University Hospital, respectively), shared their experience with the haematologists of the West region.
- Prof H. TOUHAMI mentioned a multicentred study proposed to Mediterranean countries by Laboratories France Biotechnology France, the primary objective, being to prevent any haemorrhagic accident and prevent arthropathy development in young haemophiliacs.
- Interest for substitutive prophylaxis was underlined by Dr K BENALLAL, paediatrician (Sidi bel Abbès Hospital University) who informed that 2 young haemophiliacs have already started prophylactic treatment.
- Dr R MESSAOUDI (paediatric department of the Oran specialised Hospital CANASTEL) highlighted that setting up primary prophylaxis was a priority when reporting on advanced arthropathic lesions high rate in young haemophiliacs due to frequent lack of regular adequate substitutive treatment..
- Pr H. CHAMBOST presented the 1994 WHO and WFH recommendations: *"the main objective is to prevent articulation bleeding and its consequences; to this end prophylaxis should be considered as the optimal treatment for severe A and B haemophiliacs"* This treatment should start between 1 and 2 year old and be pursued indefinitely."



### Training programme in France

#### Haematologists at the University Hospital of Strasbourg (04/2006)

- Visits of 6 haematologists (3 from Sidi Bel Abbès and 3 from Oran); 2 clinical haematologists, 3 haemobiochemists and 2 medical doctors from transfusion centres.
- The objectives aimed to collect information on:
  - the organisation and functioning of the Strasbourg CRTH
  - the different care methods (consultation for diagnosis announcement, treatment and follow up of haemophilic patients or suffering from haemorrhagic diseases)
  - the techniques of laboratory biological screening on haemophilia and haemorrhagic diseases
  - the organisation and functioning of blood donation activities



#### Physiotherapists at Osseja rehabilitation centre (05/2007)

- The objectives were to collect information on:
  - the organisation and functioning of a rehabilitation centre specialised in haemophilia in France
  - the different rehabilitation care methods of haemophilic adults and children

#### Orthopaedic surgeons at The University Hospital of Strasbourg (06/2007)

- The objectives were the following:
  - collect information on the organisation and functioning of an orthopaedic surgery centre specialised in haemophilia with more than 10 years work co-operating with Hautepierre CRTH
  - study the orthopaedic surgical care methods of adult haemophiliacs
  - assist in 2 planned surgery interventions (a priority in Algeria): a knee synovectomy and an ankle arthrodesis in 2 haemophiliacs.



#### Computer scientist at the University Hospital of Strasbourg (09/2007)

- One week training for a computer scientist (Oran University Hospital Directorate) aiming to a haemorrhagic diseases follow-up database at the Strasbourg CRTH and contributed to a first adaptation of this database for specific needs.
- This database should help to constitute the register of haemophiliacs identified in the West Algerian region.

#### Nursing officer at CHU Strasbourg (03/2008)

- The objectives aimed to collect information on :
  - The Haemophilia centre organisation
  - and various haemophilia care modalities (periodical visits, planned or emergency hospitalisation...)

### Medical consultations

#### Consultations in Oran and Sidi Bel Abbès (03,06,09/2007)

- Dr A. FARADJI and N. EL RIFAI physiotherapist (Strasbourg CRTH) participated with the haematologists from Oran and Sidi Bel Abbès in the organisation of consultations for planning needs in substitutive medicines and orthopaedic therapeutic acts for several young and adult haemophiliacs (27 SBA, 53 Oran) treated in these hospitals and coming from the wilayas of their respective areas.



#### Multidisciplinary orthopaedic consultations in Oran, Sidi Bel Abbès and Tlemcen (03/2008)

- **Participants:** Dr A. FARADJI, Dr J. LECOCCO, physical medicine and rehabilitation doctor (Strasbourg CRTH) and haematologists, re-educators, physiotherapists and orthopaedic surgeons from each hospital (Oran, Sidi-Bel-Abbès and Tlemcen).
- **Objectives:**
  - yearly evaluate the articulations clinical and radiological state, according to the WFH reference criteria and indicate the necessary orthopaedic acts
  - contribute to synoviorthesis (chemical and radioactive) practice.
- **Tools:**
  - For consultations; Bayer Laboratories (France) donated several follow-up orthopaedic files for the 3 University Hospitals
  - For synoviorthesis; Hexatrine (triamcinolone) donated by Daiichi Sankyo Laboratories (France) and radioactive Yttrium-90 supplied by the Tlemcen hospital nuclear medical service.



### Donation of material

- 1) Haemostasis reactivities at University Hospitals of Oran and Sidi Bel Abbès (09/2006)
- 2) Continuous perfusion pumps at University hospitals of Oran and Sidi Bel Abbès (06/2007)
  - *"In the framework of the twinning between the Regional Centre for Haemophilia Treatment of Strasbourg with Algerian Hospitals, specialised material for surgical interventions on haemophiliacs was offered yesterday to 2 Algerian orthopaedist surgeons participating in training at the orthopaedic surgery Centre (CCOIM, Strasbourg). Thanks to the LFB company (French Laboratory of biotechnologies) Dr Faradji, co-ordinator at the CRTH and president of the JOSSH Association (twinning Oran-Sidi-Bel-Abbès for haemophilia) donated to Drs Medjahed (Oran University Hospital) and Hamdaoui (Sidi Bel Abbès University Hospital) 2 continuous perfusion pumps for a secure distribution of anti-haemophilic medicines during operations."* Strasbourg newspaper D.N.A 19/06/2007
- 3) Synoviorthesis medication at University hospitals of Oran and Sidi Bel Abbès (03/2008)



### W.F.H assistance

- Dr A. FARADJI and J.M. BOUCHEZ, representative of the French Association of Haemophiliacs were invited to a Workshop on Administrative Aspects of Hemophilia Care (Algiers, 05/2007) organised by the WFH and the Algerian Association of Haemophiliacs.
- with representatives of the Algerian Health Ministry (Health General Director, Director of the National Blood Agency, Pharmacy Director), of the Algerian Association of Haemophiliacs and of the Medical Committee of Haemophilia.



### Perspectives

- Contributing to setting up the haemophilia and haemorrhagic disorders centre of the West Algerian region grouping the four Hospitals (Oran, Sidi Bel Abbès, Tlemcen and Béchar)
- Enhancing arthropathy prevention measures (prophylaxis, synoviorthesis, synovectomy...)
- Contributing to the planned orthopaedic surgeries for reducing the handicap duration