

French online database on bleeding disorders NHEMO: pharmaceutical contributions to the multidisciplinary network

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OBJECTIVES

In France since 2006, patients suffering of bleeding disorders are followed in health reference centers. In 2009, the "Hospital, Patients, Health and Territories" Law strengthens the cooperation between healthcare professionals and implements a specialized network of care.

For years, pharmacists have been involved in the follow-up of haemophiliac and Von Willebrand patients; within a **regional framework, pharmaceutical networking** has grown through a series of meetings and writing of procedures allowing to face emergency situations.

METHODS

In 2008, a **web-based and coordinated national data collection in inherited bleeding disorders** aimed at the continuous systematic collection, analysis, and interpretation of health data is created in France, **NHEMO (Net-HEMOstase)**. It fulfils the criteria of confidentiality of medical information under French law.

Pharmaceutical modules are included and tested in preview by the pharmacies linked to the Nantes reference center. NHEMO is used to assist in daily patient management.

RESULTS

✓ Currently, **700 patients followed by 6 regional hospital pharmacies** are included in the registry (Figure 1). The patients' treatments and medical data are available online, only by the **authorized healthcare professionals** and can be used as a help tool, especially in emergency situations.

✓ Outpatients **prescriptions** are available online (figure 2). Physicians can fulfil prescriptions for hospital pharmacists (clotting factors), community pharmacists (others prescribed drugs or medical devices) and others health professionals such as nurses... Medical certificates can also be produced for air travels.

✓ Hospital pharmacists record the **dispensations of clotting factors** for each patient, intended for the domicile or the hospitalisation use. The brand, the number of IU, the cost are compulsory noted, added with the number of exposition days and the potential scraped products for inpatients (figures 3 & 4). For each inpatient stay, a detailed assessment is produced and given to the physician.

✓ A **statistical search engine** is associated and allows to generate activity reports and to extract the mandatory data annually sent to the reference center coordinator (figure 5). Pharmacists can also tap data for their own center, by brand/pathology/type of dispensations etc...

✓ Moreover, **emergency inventories** for each hospital pharmacy involved in NHEMO are available online to help physicians to prescribe at a distance (figure 6).

Figures

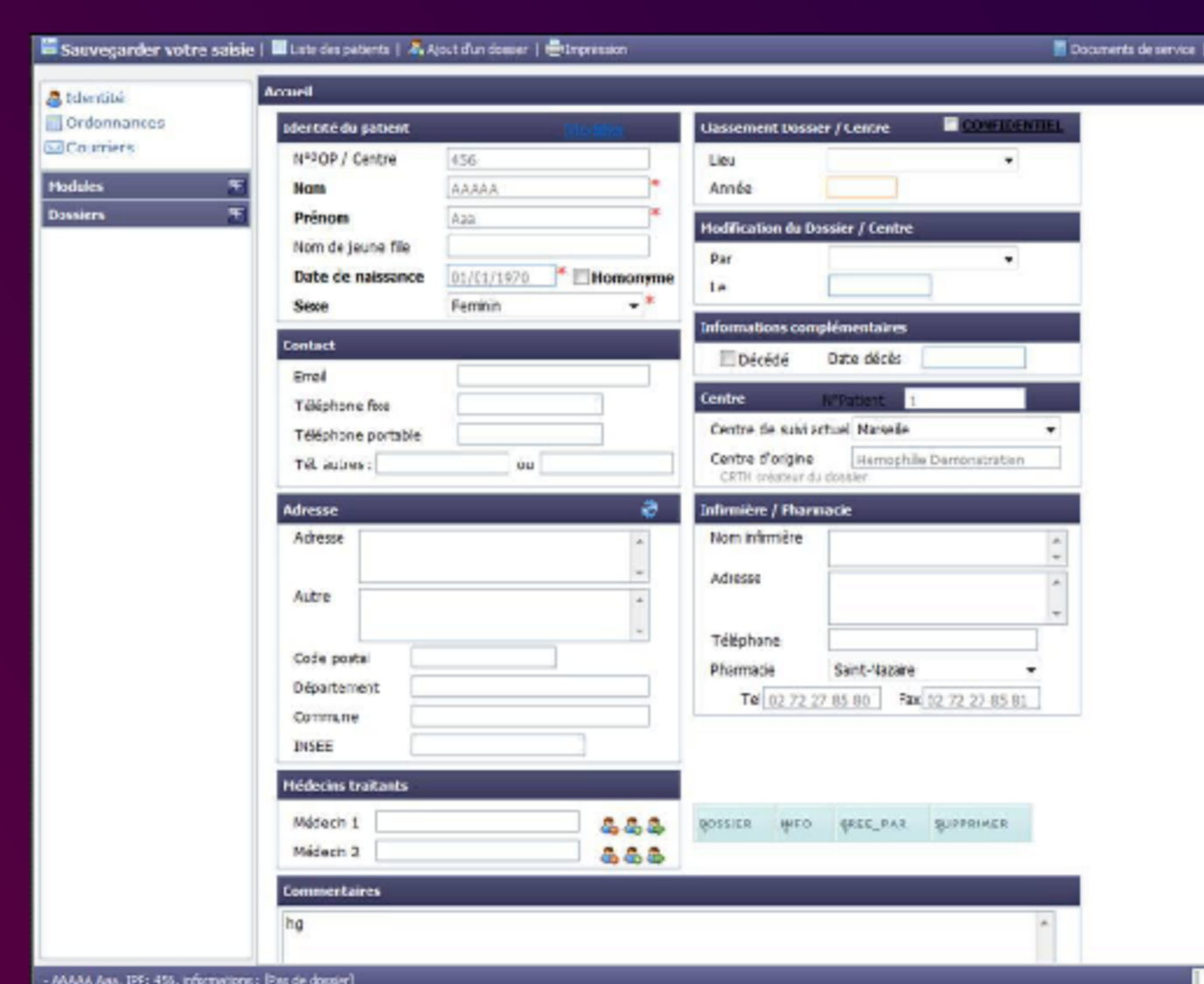


Figure 1: patients' registry form

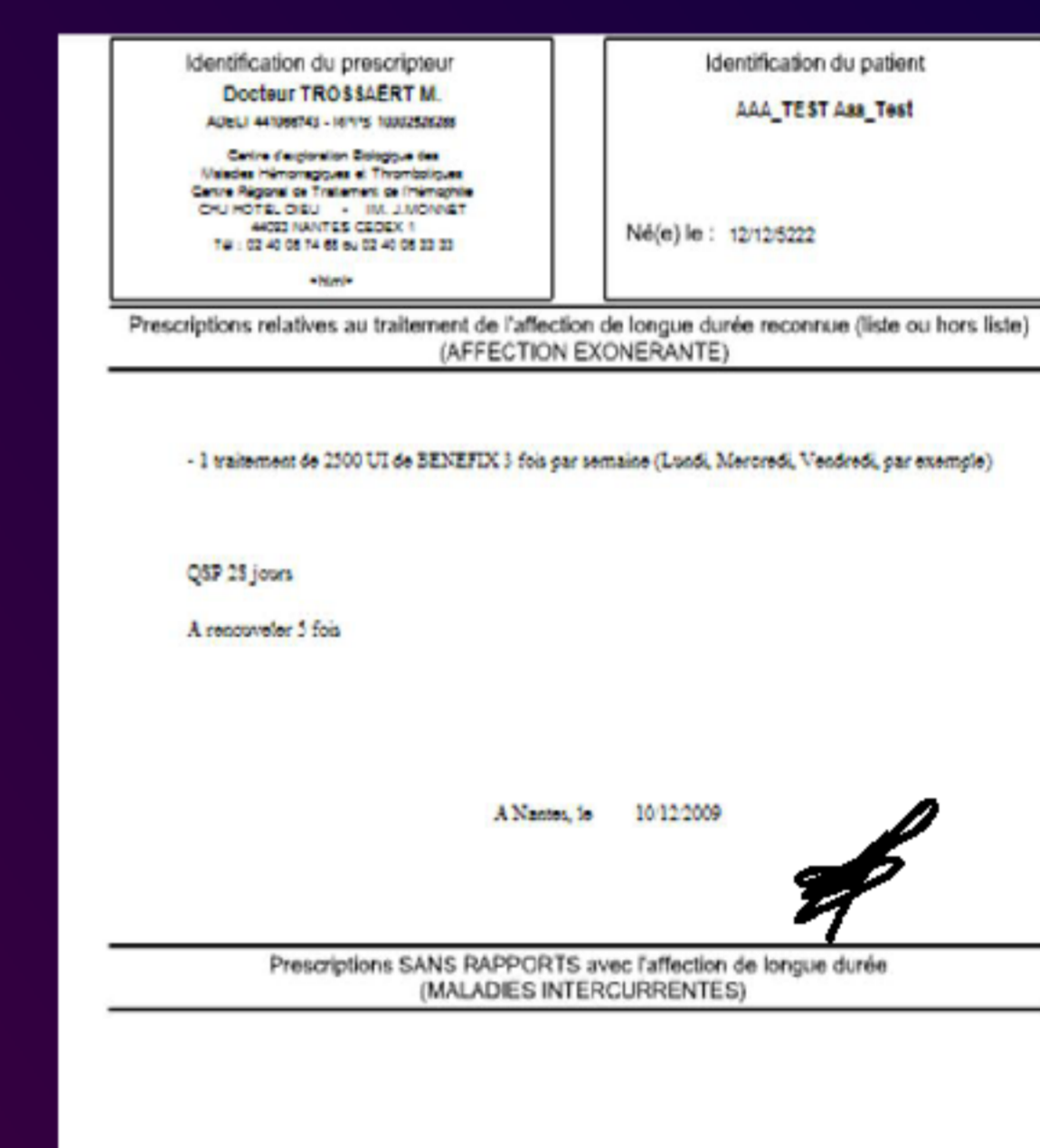


Figure 2: outpatient prescription of clotting factors, including brand, number of IU and treatment duration

Electronic signature in process

Identité	Rétrocessions																											
<ul style="list-style-type: none"> Ordonnances Courriers Modules Dossiers Hémophilie Antécédents Pathologies Consultations/Episode Infos Génotype Phénotype/Génotype Hospitalisations 	<table border="1"> <thead> <tr> <th>Type</th> <th>Date</th> <th>Type de dispensation</th> <th>PUI</th> <th>Détails prescription</th> <th>Pharmacien</th> <th>Niv. TZA</th> <th>Nb Tot</th> <th>Coût</th> </tr> </thead> <tbody> <tr> <td>Traitement à domicile</td> <td>09/04/2013</td> <td>Nantes</td> <td>PUI HSJ</td> <td>HELIKATE NEXGEN : - 1 traitement(s) de 6000 UI 3 fois par semaine (Lundi, Mercredi, Vendredi, par exemple) - 2 traitements usupit de 4000 UI par mois en cas de...</td> <td>SIGAUD ML</td> <td>Nantes</td> <td>HELIKATE NEXGEN</td> <td>Mors référentiels 80000 54791</td> </tr> <tr> <td>Traitement à domicile</td> <td>21/01/2013</td> <td>Nantes</td> <td>PUI HD</td> <td>- 5 traitement(s) de 4000 UI de HELIKATE NEXGEN A renouveler 5 fois</td> <td>SIGAUD ML</td> <td>Nantes</td> <td>HELIKATE NEXGEN</td> <td>Mors référentiels 20000 14725</td> </tr> </tbody> </table>	Type	Date	Type de dispensation	PUI	Détails prescription	Pharmacien	Niv. TZA	Nb Tot	Coût	Traitement à domicile	09/04/2013	Nantes	PUI HSJ	HELIKATE NEXGEN : - 1 traitement(s) de 6000 UI 3 fois par semaine (Lundi, Mercredi, Vendredi, par exemple) - 2 traitements usupit de 4000 UI par mois en cas de...	SIGAUD ML	Nantes	HELIKATE NEXGEN	Mors référentiels 80000 54791	Traitement à domicile	21/01/2013	Nantes	PUI HD	- 5 traitement(s) de 4000 UI de HELIKATE NEXGEN A renouveler 5 fois	SIGAUD ML	Nantes	HELIKATE NEXGEN	Mors référentiels 20000 14725
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Figure 3: outpatient's dispensation record of clotting factors, including brand, number of IU and cost in €

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Figure 4: inpatient dispensation record of clotting factors, including brand, number of IU, cost in €, number of exposition days and potential scraped products

Indicateurs d'Activité du CRMH			
SITE: 'HEMOPHILIE NANTES' Du: '01/01/2013' Au: '31/12/2013'			
Activité pharmaceutique: Suivi des thérapeutiques très coûteuses (Hospitalisations)			
Type de Fractions Coagulantes	Nb de Patients	Quantité (IU ou mg)	Coût (€)
FEIBA	1	10 000	9 525
MINIRIN	40		0
BENEFIX	10	134 500	102 694
OCTAFIX	2	20 500	13 007
ADVATE	43	948 794	917 340
HELIKATE NEXGEN	10	167 000	117 551
NBGP NOVONORDISK	1		0
REFACTO	1	500	373
REFACTO AF	7	239 750	183 822
PFC	1		0
NOVOSEVEN	1	838	519 190

Figure 5: annual activity report, from date to date, by reference center

Lieu de rétrocession	PUI	Produit	Nb	Coût
Nantes	PUI HD	FEIBA(U)	1000	20
		Antitrombine	500	5
		Antitrombine	1000	10
		Facteur IX	250	5
		Facteur IX	500	5
		Facteur IX	1000	5
		Facteur IX	2000	5
		Facteur IX	500	5
		Facteur IX	1000	10
		Facteur VIII	250	5
		Facteur VIII	500	5
		Facteur VIII	1000	5
		Facteur VIII	1500	5

Figure 6: emergency inventories by brand, for each pharmacy

CONCLUSIONS

The NHEMO database is one of the most important tool to make the pharmacists work together at a national level and to improve the quality of comprehensive care that patients require. Further developments are about to come soon : web-access for patients including electronic diaries, new database specifically designed for clinical and epidemiological research...

Topic: database and registry

Keywords: database, haemophilia, multidisciplinary, pharmacists

