

ADDENDUM 2 : Template of Committee annual report

(all cells can be expanded as needed)

Committee chair

Name of committee : Patient committee		
Chair : Elke Stienissen	Since : November 2020	Date of last election : November 2021

Committee members : name (E-mail)

Mariangela Fiorente (ALWB asbl : lymphoma)	mariangela.fiorente@alwb.be
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Activities in year **2021**

Date	Activity
January 25 th	Committee meeting
March 15 th	Committee meeting
April-June	Telemonitoring chronic lymphocytic leukemia (CLL) project from Janssen pharmaceuticals: a patient advisory board was created with patients to see if patients want to use telemonitoring or not. This project will continue in 2022.
May 17 th	Committee meeting
June-September	Survey Ideal patient brochure was launched by the BHS patient committee. There were 248 respondents and a report was send to the chairs of the BHS committees
July	Review website Roche about lymphoma: https://www.roche.be/nl/Patienten/ziekten/non-hodgkinlymfoom.html
July	We have prepared 5 additional questions for Belgian patients with lymphoma, CLL and waldenstr�om's disease (WM) for the 2022 global patient survey from the Lymphoma coalition together with dr. Van Hende.
September 20 th	Committee meeting
September	Review immunotherapy brochure Gilead
September	Review Venclyxto brochure Abbvie
September 15 th	Testimonials for lymphoma awareness day: https://nl.medipedia.be/lymfomen-nieuws/internationale-dag-van-het-lymfoom
November 22 nd	Committee meeting
November	Review CLL brochure Sandoz (Dutch and French)
December	Patient advisory board CAR T for multiple myeloma (Janssen)
During the whole year	We have gathered patient brochures and videos from pharmaceutical companies that are available for patients with a hematological disease.
During the whole year	We have gathered as many hematological patient organizations as possible within our committee. We have expanded a lot and have a lot of new members. We now have 16 (patient)organizations in our committee who represent +- 5.300 patients and caregivers.

! Please provide minutes of all this year's committee meetings !

Publications in year 2021

Survey report 'ideal patient brochure': this report was sent to all the BHS chairs.

Plan (policy, activities with approximate dates...) for next year

Committee meetings:

- January 10th
- March 24th
- May 18th
- June 22nd
- September: to be determined
- November: to be determined

Policy: Samen sterker! Ensemble plus forts!

Mission:

1. Identifying and relaying the needs of patients with blood diseases and caregivers in Belgium
2. Stimulating the collaboration between hematological patient organizations and groups
3. Informing patients and caregivers about the disease and treatment
4. Providing a forum and framework for optimal interaction with healthcare professionals (HCPs), Pharma and health coverage agencies to improve the care of patients with blood diseases in Belgium
5. Raising awareness of blood diseases in Belgium

Activities

Distributing the 2022 global patient survey for patients with lymphoma, CLL and WM: January - March

A brochure for patients with waldenströms disease: project from Janssen.

Immune thrombocytopenic purpura (ITP) Patient Day (Novartis): April 23rd.

⇒ Our committee will introduce itself on the ITP Patient day that is organized by Novartis.

Awareness campaign : September 2022

Website and flyer for patients with information about hematological diseases and all hematological patient organizations: spring-summer 2022. Our goal is to make 1 flyer that contains all patient organizations. This has the advantage that every hospital in Belgium can give this flyer to patients when they get their diagnosis. Up till now all (patient) organizations have their own flyer.

Besides the flyer we also want to make a website with information for patients and caregivers. We will keep that website up to date.

Patient pathway for multiple myeloma: project from Janssen pharmaceutical company

Brochure Clinical trials: dr. Heyrman (ZNA) contacted us to give feedback on a clinical trial brochure.

Comments / requests for the BHS board

1. Flyer and mini website – awareness

We want to make **1 flyer** with basic information about the disease and (patient) organizations which we will link to a **mini website** (hub BHS website)

The flyer will contain all hematological patient organizations that are a member of our committee and it will replace all the separate flyers from the individual (patient) organizations. This means that 1 flyer can be given to every patient with a hematological disease.

For this project we would like to have :

- Some financial support from the BHS
- Input from the health care professionals (explanation on the disease and treatments)
- Communication from the BHS to notify the hematology hospitals about the flyer and to advise them to hand out the flyer to patients with a hematological disorder
- SPOC (hemato task force) for medical questions from patients who have filled in the contact form on the website

2. Patient information

We want to provide the patient's perspective on patient information, care improvement and scientific projects. Therefore we would like to **work together with the BHS board and other committees**: a lot of pharmaceutical companies ask us to review their patient materials from a patient view. Is the text understandable, what is missing, Some of those brochures are reviewed by haematologists as well from a medical view. But it is not because something is medically or scientifically correct that it is also patient friendly and understandable for patients and caregivers.

If we create a brochure in one country's language, we would like to have a budget for translation into the other country's language.

We also want to have a better collaboration with pharmaceutical companies. We would use some help for remuneration guidelines for patient experts and templates for standard contracts.

Special fee for patients for the BHS GAM

Financial sponsoring of individual patient organizations

Collaboration with hematologists from Flanders, Brussels and Wallonia

3. Funding

We would really like to have some operational independence: own **BHS account number** so we can ask for financial support from other organizations as well. Therefore we would like **to sign contracts as well**. Of course in coordination with the BHS board, feedback moments etc. If that is not possible, we hope that other organizations can give financial support specific for the BHS patient committee.

We also would like to have a BHS patient committee **email address**.

4. Raising BHS awareness towards patients with hematological diseases/awareness campaigns

Patients and informal caregivers don't know what BHS is.

Therefore we want to use the BHS logo for webinars, projects, surveys etc. And we also want clear rules of interaction with the BHS board: what is needed to use the BHS logo for PaC activities, what kind of support can the PaC count on?

We would love to get financial support for the awareness campaigns and HCP's who want to give an interview about:

- A blood disease
- Treatments (immunotherapy, transplants,)
- Communication HCP - patient

And HCP's who want to make fact sheets about the disease (symptoms, ..)

5. Survey: we want to organize (and concentrate) surveys to identify the needs of patients and caregivers

We would like the help of HCP's to:

- Choose the topics

- Phrase the questions
- Make reliable and professional surveys