

Activity Report 2015



Belgian Polyposis Project
Hereditary Colorectal Cancer Project

Prepared for Foundation against Cancer



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Mission statement

In 1993, several physicians representing the different Belgian universities set up the scientific association FAPA (Familial Adenomatous Polyposis Association) in order to establish the national registry of patients suffering from familial adenomatous polyposis (FAP).

Only In 2011 the decision was taken to embark on registration of patients suffering from Lynch Syndrome (LS), formerly Hereditary Non-Polyposis Colon Cancer (HNPCC).

FAPA's initial aims are prevention of colorectal cancer, research in the field of hereditary colorectal cancer and enhancement of patient's quality of life by:

- Providing information about Familial Adenomatous Polyposis and Lynch Syndrome to patients and relatives;
- Supporting physicians to trace families and to guarantee regular screening and follow-up for their patients;
- Participating in national and international researches on the basis of a register: FAPA manages two registers aiming at including all Belgian FAP and LS patients anonymously;
- Stimulating informal contacts between patients, creating an opportunity to exchange experiences and to enhance social support.

Based on the experiences with the Belgian Polyposis Project, FAPA has expanded in 2011 its activities towards the Lynch syndrome. Lynch syndrome is more common, probably representing about 1-3% of all colorectal cancers. Given the cumulative risk being 5%, the population incidence of Lynch syndrome is estimated between 1:2000 and 1:660 (de la Chapelle, 2005) potentially resulting in 6000-16000 affected individuals in Belgium¹. The Lynch syndrome project consists in:

1. Developing a **national register** for LS families with two primary functions. On the first hand, to increase the understanding of LS by creating and maintaining a research resource for fundamental, clinical and epidemiological scientific research and consequently to improve

1A Belgian register for Lynch-Syndrome families. Background and rationale.
<http://www.belgianfapa.be/sites/default/files/Lynch%20syndrome%20project.pdf>

research capabilities by centralizing data; and on the second hand to serve as an educational resource for participants, their physicians and other health care providers.

2. Creating a **Biobank** for persons with a clinical suspicion of LS but with a negative genetic test.

Informing patients & providing support

One of the major goals of FAPA is to inform and to offer support to patients. We tried to achieve this goal in different ways in 2015.

Contacts with patients

New patients were visited (home visit or hospital visit) at their request in order to inform them about FAPA, their affection, to support and to obtain their informed consent. Each new patient was contacted by telephone and the majority accepted to see a FAPA-representative. At this occasion a FAPA worker draws patients' family tree and emphasizes the importance that all persons at risk are seen by specialists. Follow-up home visits are only performed at patient's request.

In total, 37 patients were visited at home by a FAPA team member in 2015.

Other follow-up contacts took place by phone or by mail (directly or through the contact form). By this way patients can ask some specific questions. FAPA received 28 contact forms (20 Flemish and 8 Walloon) from visitors of the website.

At some points, a board member was contacted for advice due to the medical specificity of the question. Some patients also requested contacts with other patients especially in emotional complex circumstances (before surgery, before the first screening ...).

Information about all patient contacts is kept in order to have a record of these. Over the year 170 contacts took place with patients either by phone or through e-mail.

	Visits	Other contacts	Newsletters
Patients and family	37	170	
FAP	5	64	277
Lynch	32	106	41

These figures do not take into account the contacts we had with a group of patients (i.e. for the info days, Polyposis Contact Group...).

Info days

An Info day for patients and families was organised on Saturday 14th of March in Brussels. Parallel sessions in Dutch and French welcomed 60 patients from all over the country. Information about research in genetics was brought by Prof. Kathleen Claes (UZ Gent) and Prof. Dahan (IPG). Info on surgery was delivered by Dr. de Buck van Overstraeten (UZ Leuven) and Prof. Léonard (UCL-St Luc). Other discussed subjects during this info day were 'insurance' (Partyka law) and the socio-economic impact of a chronic disease. Mme Emilie De Smet, Secrétaire politique d'Altéo, mouvement social de personnes malades, valides et handicapées, has emphasized the role of the health insurance employees in analysing each situation as an original, single one case: patients encountering financial difficulties related to their affection should ask for an interview in order to discuss their specific case. M. Geert Vanmeldert from 'Christelijke Mutualiteiten' focused on the social issues for the Dutch speaking public.

Newsletter for patients

In 2015, registered patients received two Newsletters in order to inform them about the activities of FAPA (*see appendix 1*). In these Newsletters, the activities organised by the Foundation against Cancer such as the different symposia, RAVIVA and Relay for Life were also announced. For quite a few families, the newsletter remains the most effective way to communicate and to reach them with messages about both diseases and their consequences. A digital version of the newsletter is planned for the near future, as with Lynch Syndrome, our public and target group gets younger and more digital-minded.

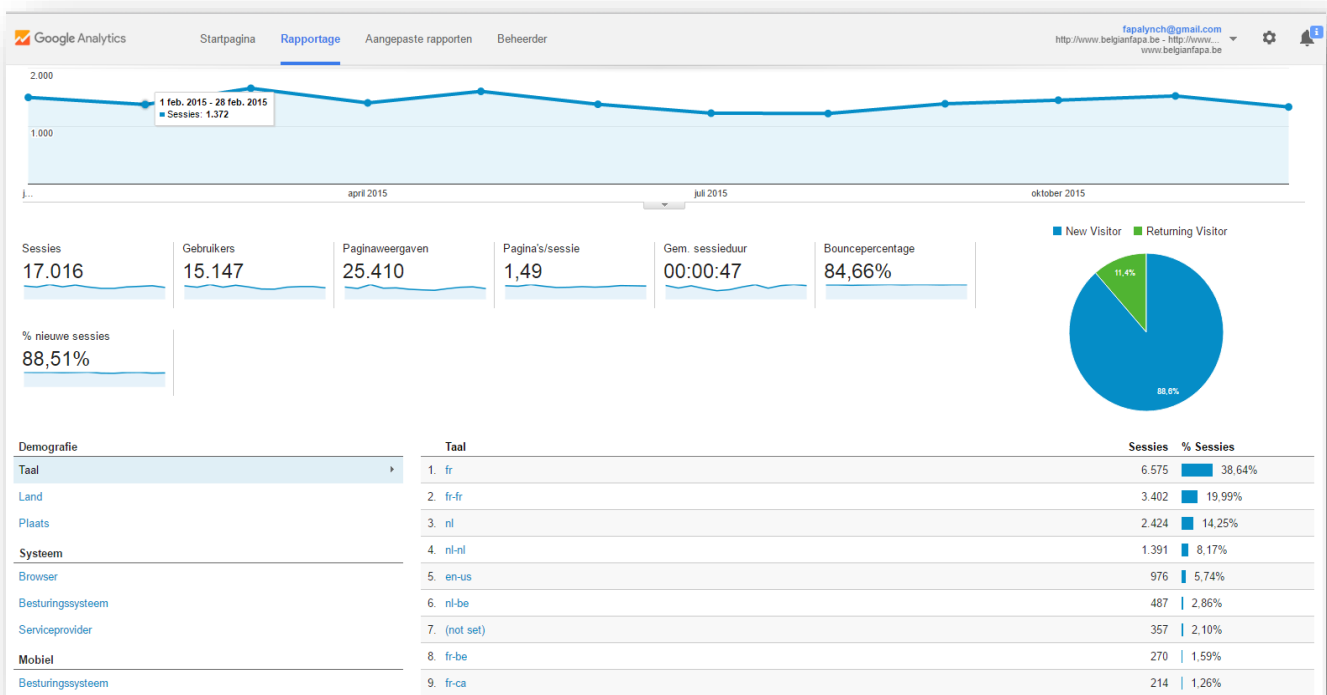
Website

The FAPA website (www.belgianfapa.be) is continuously updated:

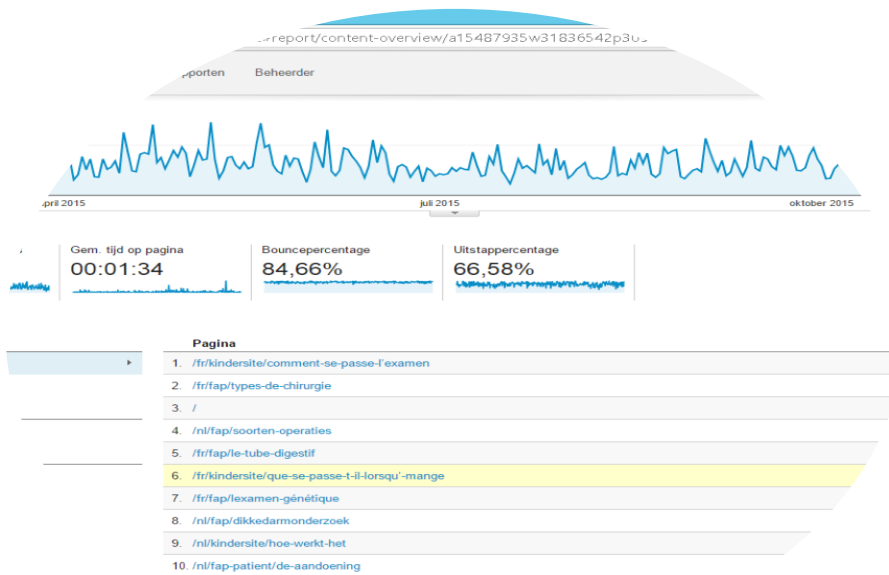
- The newsletter is available on the website.
- Activities are announced: specific activities organised by FAPA (i.e. info days) as well as activities organised by the Foundation against Cancer (e.g.: Relay for Life, symposia...).
- New, up-to-date information about FAP and LS is available on the website.

The website encounters an increasing success, especially the pages for youngster and children (see analytics figure 2). In the top 10 pages, 3 are related to the children-site. The item on the children-site 'Comment se passe l'examen' is the most frequently visited page.

In 2015, the site had 15.147 visitors (figure 1). Numbers have increased after the expansion of FAPA's activities towards Lynch Syndrome. The website has thus become an essential way of transmitting information. During March (colorectal cancer month + Infoday), more than 1500 visits were registered, differing from the usual 1200-1300 monthly registrations.



1. Visitors @ www.belgianfapa.be



2. Top 10 most visited pages @ www.belgianfapa.be

Brochure – leaflets

In 2015, FAPA continued the distribution of brochures and flyers, especially the brochure about Lynch syndrome. Whenever FAPA collaborators visit patients or doctors (at home or in the hospital) or hold an info stand, folders and brochures are given to inform as many patients as possible. Hospitals with whom a collaboration is established have brochures at their disposal.

FAPA also disposes of folders for kids and young adults and a brochure on nutrition.

Informing physicians

Another major goal of FAPA is to inform doctors and physicians about FAPA and its register, to help them in tracing and informing FAP and LS patients as well as to ensure early detection and regular follow-up.

Research has shown that a central register (for FAP as well as for LS), which participates in coordinating screening guidelines and education about the affection, substantially increases survival rates. Therefore FAPA aims at increasing its participation in the coordination of screening guidelines and education about FAP and LS.

FAPA has a good contact with doctors in the main university hospitals but has developed collaborations with a large number of regional hospitals (see list below). At the beginning of the FAPA project, only gastroenterologists and surgeons were reached by the FAPA team. At the moment and with the expansion to the LS, geneticists, gynaecologists, urologists... are also contacted. General practitioners are informed when their patients are included into the registry. FAPA team members made 57 visits to hospitals in order to see gastroenterologists and other specialists (geneticists). 110 contacts were registered with professionals, either by telephone or mail.

Contacts 2015	Visits	Other contacts	Newsletters
Professionals	57	110	360

Several axes are used to inform the doctors involved with FAP and LS:

- On the website, doctors can find general information as well as guidelines for screening and follow-up of FAP and Lynch patients. These guidelines were developed by FAPA and based on existing international expert guidelines (e.g. Amsterdam criteria). These guidelines can also be downloaded and are provided to physicians during hospital visits for registration.
- Brochures as well as guidelines for screening and follow-up of both affections are distributed to physicians via a 'guided, personalized' mailing after contact with gastroenterologists, surgeons, geneticists...
- When a new contact is established with a doctor in order to set up collaboration for registration, he also receives all documents available in order to inform patients about the disease and its treatment (e.g. patient brochure, FAPA leaflet, leaflet for children, invitation for info days etc.).
- In 2015, we kept on informing physicians about the activities of the FAPA via our Newsletters (*see appendix 2*) sent to all contacts of FAPA's own mailing list and to the members of these organisations:

- the “Vlaamse Vereniging voor Gastro-Enterologie (VVGE)” and the “Société Royale Belge de Gastro-entérologie” (SRBGE)
- In order to create awareness and to inform the doctors-specialists about FAP and LS, FAPA held in 2015 an information stand at:

The BGDO (Belgian Group of Digestive Oncology) symposium – 10/1/2015
The Belgian week of Gastroenterology, Brussels – 25-28/2/2015
Belgian Surgical week – 7-9/5/15

The presence of FAPA on these occasions is crucial because it is effective to reach professionals involved in treatment and follow-up of patients. Doctors then are easier to approach and more receptive for contact and information.

It nevertheless remains one of the biggest challenges for FAPA to get access to patients’ data in hospitals even if the patients mandated FAPA for this by signing an informed consent form. A lot of time and energy is spent in getting in touch with the right person, then convincing him/her to give FAPA the means to accomplish its objectives of data registering. FAPA is actually looking at facilitating this aspect of its task.

Registration of patients: progress

FAPA is in charge of the national familial adenomatous polyposis (FAP) and Lynch syndrome (LS) registers, which operates as a basis for scientific research.

Registration of FAP patients started in the university hospitals. Since 2005, registration of FAP patients has also taken place in non-university hospitals. A stepwise approach has been developed for the registration. Hospitals are contacted by means of an introduction letter explaining the Belgian Polyposis Project. This letter is followed by a telephone contact. If patients are followed in the hospital, a personal contact is necessary to set up the collaboration. Afterwards, follow-up contacts are necessary to ensure a long-term continuation of the collaboration (new patients, update files...).

At the end of 2015, collaboration had been established in these hospitals.

CHC Clinique Saint-Joseph	Liège
CHU Liège - site Sart-Tilman	Liège
CHC Clinique Ste Elisabeth	Heusy
Hôpital Civil	Charleroi
IPG - Institut de Pathologie et de Génétique	Gosselies
Centre Hospitalier de Jolimont	La Louvière
CHU Tivoli	La Louvière
CHU Dinant-Godinne	Namur
Clinique Ste. Elisabeth	Namur
CHU Notre Dame Bruyère	Chênee
Clinique St-Pierre	Ottignies
Cliniques universitaires St Luc	Bruxelles
CUB Erasme	Bruxelles
Institut Bordet	Bruxelles
CHIREC	Bruxelles
Clinique St Jean	Bruxelles
AZ St-Jan	Brugge
AZ St Lucas	Brugge
AZ Groeninge	Kortrijk
AZ Damiaan	Oostende
H. Serruys	Oostende
St AndriesZH	Tielt
Jan Ypermanziekenhuis	Ieper
H.Hartziekenhuis	Roeselare
Stedelijk ziekenhuis	Roeselare
St. Jozefskliniek	Izegem
UZ - Gent	Gent
Jan Palfijn	Gent
AZ Maria Middelaes	Gent
OLV-ziekenhuis	Aalst
Algem. Stedel. Ziekenhuis	Aalst
AZ St Blasius	Dendermonde
AZ Nikolaas	St. Niklaas
ZOL, campus St-Jan	Genk
Jesseziekenhuis Hasselt - campus Salvator	Hasselt
MZNL	Lommel
St-Trudo ziekenhuis	Sint Truiden
UZA	Antwerpen
ZNA Middelheim	Antwerpen
AZ Klina	Brasschaat
Koningin Paola kinderziekenhuis	Antwerpen
St Vincentiusziekenhuis	Antwerpen
GVA Sint-Augustinus	Wilrijk
H. Hartziekenhuis	Lier
AZ St Elisabeth	Herentals
St Jozefziekenhuis	Turnhout
AZ St. Jozef	Malle
Universitair Ziekenhuis	Leuven

All are at least contacted by FAPA collaborators once a year. It guarantees that newly arrived doctors are well informed and that the others keep FAPA in mind if a new FAP or Lynch patient is detected.

FAP project

Patients have to sign a written consent so that FAPA can register their data. In 2015, **11** new FAP-patients signed a written consent in order to integrate the national register. It means that at the end of 2015 we counted **397** FAP patients who signed the consent form. The very low prevalence of FAP amongst the population precludes higher growth rate of the register(*see appendix 3a*).

The new database for FAP, adapted to ease data retrieval for future statistical analysis, has been finalised at the end of 2014. Then FAPA team members have started to transfer the data from the old FAP database to the new one. FAPA has taken advantage of this opportunity to review and complete medical records of patients.

Lynch project

Based on the experiences with the Belgian Polyposis Project, FAPA has expanded its activities by creating a register for LS families with two primary functions: research and educational resource . In addition a Bio Bank is created for family members who have been tested and where there was no mutation found.

FAPA has progressed continuously within this project. In 2015, **49** new Lynch patients signed the consent form, indicating their agreement to enter the database. At the end of 2015, **93** LS patients have been integrated in the LS registry (*see appendix 3b*).

Explicit and common guidelines are needed for patient identification, treatment and follow-up. Primary care physicians and specialists can play an important role in the identification and management of LS and therefore their awareness of guidelines for genetic counselling and testing is important and has to be supported².

Focussing on these facts, FAPA took the following actions in 2015:

² Lynch syndrome: genetics, natural history, genetic counselling, and prevention.
J Clin Oncol. 2000 Nov 1;18(21 Suppl):19S-31S
Lynch HT1, Lynch J.

- Develop contacts with the genetic centres in order to convene on how to reach doctors and patients.
- Continue the distribution of the Lynch brochure and the guidelines to physicians via a guided, personalised mailing.
- Complete the Lynch registry, with the PROGENY software (www.progenygenetics.com) as the architecture of the database.
- Elaborate pedigrees of the LS families and collect medical data of the patients who signed the consent form.
- Host the database by an external partner for safety reasons (Disprimo IT Solutions).

Research projects

Regarding the scientific aim, a publication based on our FAP-registry is planned. The aim will be to analyse the adenomatous familial polyposis data from the registry, gathered during the last decade, in order to compare patient's outcome with other national registries in Europe and elsewhere in the world. This "benchmarking" will help us identifying the necessary adaptations and improvements in the management of FAP patients.

Meetings

In order to create awareness about FAP and LS amongst the public, FAPA held an information booth at several occasions.

Where	When
LUSS-day St. Luc	26/1/15
Prévention et dépistage, Saint Luc, Bruxelles	6/2/15
LUSS-day, CHR Citadelle, Liège	19/3/15
Semaine des associations des patients, Soignies	18/5/15
Conférence 'Qualité de vie', Bruxelles	4/6/15

FAPA-team

FAPA team counts 3 collaborators (2,25 FTE). Juan-Francisco Asueta-Lorente started end 2014. His work in the French speaking part of Belgium resulted in intensified collaboration with hospitals by the end of 2015 . Consequently more patients have been referred to FAPA by doctors.

After obtaining consent, FAPA collaborators collect on a daily basis medical data related to FAP and Lynch syndrome in the different centres where the patients are or have been treated. Each FAPA colleague is responsible for a region in Belgium. Considering many patients are followed in different hospitals, close collaboration between FAPA collaborators remains necessary. Therefore, FAPA team-meetings (FTM) take place in order to discuss individual and organisational tasks and issues monthly. Furthermore, weekly phone communications have a good impact on the work organisation. Members of FAPA-board attend the team-meetings on a regular basis in order to answer to remaining questions. For data collection FAPA-team members operate under the supervision of doctors and/or geneticists of the board.

Team 2015	
Myriam Renson	myriam@belgianfapa.be
Anne Delespesse	anne@belgianfapa.be
Juan-Francisco Asueta-Lorente	jean-francois@belgianfapa.be

Board meetings are organised 4-5 times a year. During these meetings FAPA team members give an overview of the work and current questions and problems are discussed.

Once a year, FAPA holds his General Assembly (*see appendix 4*).

Composition of the FAPA board in 2015:

President

Prof. E. Van Cutsem, UZ – KU Leuven, department of gastroenterology

Vice-president

Prof. K. Dahan, UCL – St Luc, department of medical genetics

General Secretary

Prof. D. Léonard, UCL – St Luc, department of colorectal surgery

Treasurer

Prof. S. Laurent, UZ - Gent, department of digestive oncology

Members

Prof. K. Claes, UZ - Gent, department of medical genetics

Dr. B. Dessars, ULB – Erasme, department of medical genetics

Prof. D. Franchimont, ULB – Erasme, department of gastroenterology

Prof. A. Kartheuser, UCL - St Luc, department of colorectal surgery

Prof. K. Leunen, UZ – KU Leuven, department of gynaecology oncology

Dr. O. Plomteux, CHC St Joseph – Liège, department of gastroenterology

Prof. S. Tejpar, UZ – KU Leuven, department of gastroenterology

Dr. A. Wolthuis, UZ – KU Leuven, department of abdominal surgery

Budget

We thank the Foundation against Cancer for its logistic and financial support (for financial detail: *see appendix 5*) for the last 3 years. Indeed, the achieved objectives could not have been reached without this financial support.

Despite different efforts from FAPA to get an extra financial support, FAPA depends financially exclusively from the donations of the Foundation, except some very small financial contributions from FAP-patients in the past. The fundraising aspect will be analysed thoroughly during 2016.

Future perspectives

FAPA will *continue* to work towards accomplishing its main objectives related to FAP and Lynch Syndrome. In 2016 FAPA will focus on

- expanding contacts with LS patients and continue the registration of the patients;
- creating awareness amongst doctors and the public about hereditary colorectal cancer and the importance of genetic screening;
- disclosing scientific data; the FAP-registry will be used as a research resource;

- organising info days for FAP and LS patients and stimulate informal contacts between patients (by the organisation of a Polyposis Contact Group- working group meeting for example);
 - recruiting a new team-member whose mission will partially be to intensify external communication.
- These objectives are defined in an action plan 2016 with clear, specific and measurable goals.

FAPA would also like *to develop* a Belgian register of at-risk patients for pancreas cancer (FAPACA patients, Familial Pancreatic Cancer) and this could very well resemble the actual Lynch register. Trying to find the best way to identify these, FAPA concluded that geneticists are in the best position to do so. In the future, FAPA could become the expertise center for different kinds of hereditary cancer.



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