College of Genetics – Activity Report 2014

Marc Abramowicz, President College of Genetics

Elfride De Baere, Vice-president College of Genetics

1. Composition of the College:

The composition of the College remained unchanged since its creation on 26 november 2012. The daily coordination of the activities of the College is performed by the President (prof. Marc Abramowicz) and the vice-President (prof. Elfride De Baere).

2. Meetings of the College:

The college held its monthly plenary meeting at following dates: 14/02/14, 14/03/14, 4/04/14, 9/05/14, 6/06/14, 4/07/14, 5/09/14, 3/10/15, 7/11/15, 5/12/15.

The approved minutes of these meetings were circulated among all College members via email and will be available on the future College's website, www.collegegenetica.be (not active yet). An overview of the main realisations and priorities of 2014 is given in the points below.

3. Main activities of 2014:

a) Communication/visibility

- In the Pluriannual plan of the College (2014), we aimed to better integrate the activities and the visions of the College of Genetics and other Colleges, stakeholders and authorities. Therefore constructive discussions were held between the College of Genetics and the KCE, High Health Council, RIZIV (**see also c.**) and several strategic meetings were attended.

- Prof. Abramowicz represented the Belgian genetic centers, together with Prof. Gert Matthijs, at the meeting of Global Leaders in Genomic Medicine, Genomic in Medicine 6th meeting, National Human Genome Research Institute, Washington, DC, USA, Wednesday, 8 January 2014 - Thursday, 9 January 2014. http://www.bemgi.be/nhgri-global-leaders-meeting/

- Prof. Abramowicz represented the Belgian genetic centers at the EUROPLAN national conference that took place on 28/2/14: http://www.eurordis.org/sites/default/files/flags/finalreport-belgium.pdf

- In order to facilitate visibility, the creation of a portal (website www.collegegenetica.be) of the College of Genetics was initiated with support of the company GripGraphics. A newsletter will be part of this initiative. There will be integration with portal sites of other Colleges, e.g. the College of Oncology. It can be

anticipated that the website will be accessible in Spring 2015. Task leader: Prof. Geert Mortier.

b) Harmonisation of reporting

- Currently multiple reports are expected from the College and the genetic centers. It is our aim to harmonize the reports in terms of contents, format, and reporting dates. In the Pluriannual plan of 2014 four work packages (WPs) were defined. Following WPs were initiated in 2014:

  - **WP1.** Write clear definitions of the activities to ensure uniform in house registration regarding:
    - Laboratory activities
    - Tests performed abroad
    - Clinical activities
      - As part of convention genetic counselling
      - Not part of convention genetic counselling

    This work package will need input from the representatives from the genetic centres and at least 3 meetings will be held to address these questions.
    This work package is ongoing.

  - **WP2.** Design a common electronic format for **registration and reporting** that takes into account that the different centres are using different electronic record systems. These electronic records are frequently part of the global University Hospital records system and each system has its own possibilities and limitations. The electronic data should be reported in the same format to allow merging of data in one global report for the country. This work package needs **input from IT managers of each genetic centre** and local electronic record keeping has to be adapted to be able to generate a common format. This will cost each centre additional hours of IT support. It is difficult to predict how many meetings will be necessary to find the common denominator of the different IT systems used in the genetic centres. By making the first yearly report for art 33 and for the convention "Genetic Counselling", we obtained more insight into the problems with these reports. We need **input from specialized IT consultants** to finish this work package (12 hours during the meetings and at least 20 hours to provide us with a common database format).
    This work package is ongoing.

  - **WP3.** Design an electronic format for reporting to the **registers for rare diseases and cancer**. It will be important to decide what parameters have to be collected and reported. This work package will need input from the responsible people of the rare diseases register and cancer register. We will depend on input from the registers to proceed. Here we will also need input from our local IT managers and from the IT managers of the registers and from specialized IT consultants.
    A meeting with WIV representative Urbina Paz Montse (www.wiv-isp.be) was held at the College meeting of 7/11/14. Following point was discussed: the implementation of National Plan of Rare Disorders, Action plan 16.

The KB/AR regarding Rare disorders dates from 25/04/14 and was published in the Belgisch Staatsblad / Moniteur Belge on 8/08/2014. — *Koninklijk besluit waarbij sommige bepalingen van de gecoördineerde wet van 10 juli 2008 op de ziekenhuizen en andere verzorgingsinrichtingen, toepasselijk worden verklaard op de functie 'zeldzame ziekten' / 25 AVRIL 2014.—Arrêté royal rendant certaines dispositions de la loi du 10 juillet 2008 coordonnée sur les hôpitaux et autres établissements de soins applicables à la fonction « Maladies rares » [C − 2014/24242].*

- **WP4.** The group of representatives of all genetic centres has met with people from the **RIZIV/INAMI** to simplify the reporting. Now reports are needed before 31 March, 30 April, 30 June, 30 September, 30 November. It might be more efficient to reduce the number of reporting dates and combine deadlines for reporting. We met with a representative from the RIZIV/INAMI (dr. Genevieve Haucotte) at following date: 25/11/2014.

- Task leader: Prof. Eric Legius

c) Quality/guidelines

- The College contributed to the development of different guidelines. The College and representatives of Belgian genetics centers collaborated with the KCE and the High Health Council on following reports:

- **KCE report 222: De niet-invasieve prenatale test (NIPT) voor trisomie 21 – Gezondheidseconomische aspecten**

- Authors: Frank Hulstaert (KCE), Mattias Neyt (KCE), Wilfried Gyselaers (Ziekenhuis Oost-Limburg Genk en Universiteit Hasselt). Coordinators: Leen Verleye (KCE), Leen Van den Eeden (Thomas More Instituut, Lier), Pascale Jonckheer (KCE), Irina Cleemput (KCE), Raf Mertens (KCE). Stakeholders: Marc Abramowicz (Hôpital Erasme, Bruxelles), Bettina Blaumeiser (Universiteit Antwerpen), Pascal Borry (KU Leuven), Caroline Daelemans (Hôpital St-Pierre, Bruxelles), Petra De Sutter (UZ Gent), Eric Legius (UZ Leuven), Luc Decatte (UZ Leuven), Geneviève Haucotte (INAMI – RIZIV), Björn Menten (UZ Gent), Geert Mortier (UZ Antwerpen), Nan Okun (Mount Sinai Hospital, University of Toronto, Canada), Bruce Poppe (UZ Gent), Geneviève Schamps (UC Louvain), Elke Sleurs (UZ Gent), Jean-Francois Vanbellinghen (IPG, Gosselies), Herman Van Oyen (WIV – ISP), Christine Verellen-Dumoulin (IPG, Gosselies), Joris Vermeesch (UZ Leuven), Patrick Waterbley (FOD Volksgezondheid – SPF Santé Publique), Bert Winnen (RIZIV – INAMI). Reviewers: Lieven Annemans (UGent), Jean-Jacques Cassiman (KU Leuven), Yves Ville (Hôpital Necker, Paris, France)

- https://kce.fgov.be/sites/default/files/page_documents/KCE_222As_niet_invasieve_prenatale_test_Synthese.pdf

- https://kce.fgov.be/sites/default/files/page_documents/KCE_222_Non_invasive_prenatal_%20test_Report.pdf

  An *ad hoc* Working Group NIPT was created in 2014. Members: Prof. Bettina Blaumeiser, dr. Julie Desir, Prof. Björn Menten, Prof. Eric Legius, Prof. Maryse Bonduelle. This Working Group held several meetings, one of which with dr. Marc Moens (as representative TGR) on 24/12/14. On the basis of the KCE and HGR reports and recent developments, the College submitted a request for reimbursement of NIPT with the TGR.

- **Publication of the High Health Council nr. 8912: Implementatie van niet-invasieve prenatale genetische screening van trisomie 21 (Syndroom van Down) in de Belgische zorgpraktijk**):

- http://www.health.belgium.be/internet2Prd/groups/public/@public/@shc/documents/ie2divers/19095725.pdf

- **KCE report 236: Oncogenetic testing and follow-up for women with familial breast/ovarian cancer, Li-Fraumeni syndrome and Cowden syndrome.**

- Authors: Jo Robays (KCE), Sabine Stordeur (KCE), Frank Hulstaert (KCE), Tom van Maerken (UZ Gent), Kathleen Claes (UZ Gent), Nicolas Janin (Cliniques universitaires Saint-Luc), Gert Matthijs (KULeuven), Daphné ‘t Kint de Roodenbeke (Institut Jules Bordet), Martine Berlière (Cliniques universitaires Saint-Luc), Hans Wildiers (KULeuven), Bruce Poppe (UZ Gent). Coordination: Sabine Stordeur. Reviewers: Germaine Hanquet (KCE), Françoise Mambourg (KCE), Raf Mertens (KCE). Stakeholders: Marc Abramowicz (College of Human Genetics), Bettina Blaumeiser (Vlaamse Vereniging voor Obstetrie en Gyneacologie (VVOG)), Frédéric Buxant (Groupement des Gynécologues Obstétriciens de Langue Française de Belgique (GGOLFB)), Birgit Carly (Royal Belgian Society for Surgery (RBSS)), An Claes (Vlaamse Liga tegen kanker), Pino Cusumano (SBS – BVS), Karin Dahan (Belgian Society for Human Genetics (BeSHG)), Laurence Delle Vigne (GGOLFB), Pascale Hilbert (BeSHG), Jacques De Grève (Belgian Society of Medical Oncology (BSMO)), Bart Garmyn (Domus Medica), Karin Leunen (VVOG), Ward Rommel (Vlaamse Liga tegen kanker), Didier Vander Steichel (Fondation Contre le Cancer – Stichting tegen Kanker), Susanne Crombach (BRCA.be). External validators: Ora Karp Gordon (UCLA Geffen School of Medicine, Los Angeles, USA), Eric Legius (UZ Leuven), Catherine Sibille (Institut Jules Bordet), Marc Tischkowitz (Department of Medical Genetics, University of Cambridge, UK)

- https://kce.fgov.be/sites/default/files/page_documents/KCE_236_oncogenetic%20testing_Report.pdf

- **KCE report 220: Oncogenetic testing for Lynch syndrome and familial adenomatous polyposis.**

- Authors: Jo Robays (KCE), Bruce Poppe (Universitair Ziekenhuis Gent). Coordinators: Sabine Stordeur (KCE) Frank Hulstaert (KCE). Reviewers: Germaine Hanquet (KCE), Raf Mertens (KCE). Stakeholders: Marc De Man (gastroenterologist, OLV Ziekenhuis Aalst), Nicolas Janin (geneticist, Université catholique de Louvain), Patrick Pauwels (pathologist, UZ Antwerpen), Christine Sempoux (pathologist, Cliniques universitaires Saint-Luc), Isabelle Sinapi (medical oncologist, Grand hôpital de Charleroi), Marijke Spaepen (molecular biologist, geneticist, UZ Leuven), Sabine Tejpar (digestive oncologist, UZ Leuven), Urielle Ullmann (geneticist, Institut de Pathologie et de Génétique), Jenneke van den Ende (geneticist, UZ Antwerpen), Marc Abramowicz (College of Human Genetics and Hôpital Erasme-ULB), Claude Cuvelier (Belgische Vereniging Pathologie and UZ Gent), Jacques De Greve (Belgische Vereniging voor Medische Oncologie and UZ Brussel), Marc Peeters (Belgische Vereniging voor Medische Oncologie and UZ Antwerpen), Eric Van Cutsem (Belgian Group of Digestive Oncology and president of the patient organisation Familial Adenomatous Polyposis Association (FAPA) and UZ Leuven). External reviewers: Eric Legius (UZ Leuven), Patrik Vankrunkelsven (Katholieke Universiteit Leuven and CEBAM), Hans Vasen (Stichting Opsporing Erfelijke Tumoren, Leiden, Nederland)

- https://kce.fgov.be/sites/default/files/page_documents/KCE_220_Oncogenetic%20testing.pdf

d) Specialty of clinical genetics

- An *ad hoc* Working Group Specialty Clinical Genetics was created in 2014. Members are: Prof. Koen Devriendt (president), prof. Marc Abramowicz, prof. Elfride De Baere, prof. Olivier Vanakker, prof. Isabelle Maystadt, prof. Peter Vandenberghe. The Working Group held several meetings.

- The Specialty of Clinical Genetics (Titre particulier) has been discussed with the Groupe Titres in January 2014 and December 2014. The Working Group Specialty Clinical Genetics prepared a final text that was presented at the "plenaire vergadering van de Hoge Raad van geneesheren-specialisten en van huisartsen" on 26th of February 2015. The approved text will be posted on the future website of the College of Genetics.