

A) Cover Page

- 1) **Title:** Improvement of diagnosis and treatment of adulthood post radiation GH deficiency in survivors of childhood cancer

Grant ID number: 34584213

Main collaborators:

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Société française d'endocrinologie

Société française d'endocrinologie et diabétologie de l'enfant

Société française de cancérologie de l'enfant

Patients' associations: "Les aguerris" , "Grandir" and "Craniopharyngiomes Solidarité"

2) Abstract:

The goal of this project is to improve the quality of medical management of adult survivors of childhood cancer, in terms of assessment and treatment of pituitary and GHD deficiency.

Methods: To create a website providing information on childhood cancer's late endocrine sequelae and a free MOOC dealing with post-radiation pituitary deficiency and its treatment over life and to offer on-line support and guidance to patients, relatives and medical practitioners in order to assess its efficiency in terms of percentage of patients that would be referred in Endocrinology departments and decrease in patient follow-up lost rate during transition and improve quality of information and level of health education in survivors and GPs about the long term consequences of their deficiencies.

Assessment: The satisfaction with the content, usability and design of the MOOC will be studied by a specific questionnaire completed at the end of the training. The number of website visits will be counted as well as the number of registrations to the MOOC.

To evaluate the improvement in the rate of survivors who restart endocrine follow-up, or who remain on GH therapy after adolescence, a specific questionnaire will be sent to every participant in the MOOC, 6 and 12 months after their participation.

The perceived improvement in knowledge about childhood cancer late endocrine effects in survivors and medical practitioners will be addressed by the analysis of the difference in the quiz answers before and after the specific training with the MOOC.

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C) Reviewer Comment

Comment 1: « The panel members did suggest that plans for long-term maintenance and update of the database be included in the full proposal »:

We explain on page 8 that the MOOC and webpage will be available for free with no time limit. This project is not intended to create a database.

Comment 2: « as well as a more detailed description of the MOOC and further information on how to evaluate the success of the MOOC ». See page 8-10

Comment 3: « The QoL tool used to show impact on patient and measured physician practice change should be identified, and the organisation’s experience of using the tool described. »

This project is not intended to show impact on QoL of cancer survivors but on their knowledge on pituitary deficiency and growth hormone therapy. The questionnaire that will be used to measure physician practice change is not yet available but the first basis is detailed on page 10 . A secondary analysis of the impact of these patients’ medical care change on their QoL will be considered at longer term. It is not planned in this funding request because it would require a longer follow-up. We rely on the epidemiology team (Agnès Dumas and Florent de Vathaire) expertise of using these tools in social research. See their biographical sketches in appendix.

D) Main Section of the proposal

1) Overall Goal & Objectives:

The goal of this project is to improve the quality of medical management of childhood cancer survivors when they reach adulthood, in terms of assessment and treatment of pituitary deficiency, particularly growth hormone deficiency (GHD).

a) Hypothesis:

Most of Growth Hormone (GH) deficient adult patients due to childhood cancer treatment are lost to endocrinological follow-up after pediatric care because of a lack of information on the benefits and absence of risks of GH therapy in this population of survivors.

Individuals who are better informed are more likely to adopt health-protective behaviors (such as undergoing regular medical checkups or compliance to their treatments).

Informing General Practitioners (GP's) should favor the referring of these patients to endocrinology services.

b) Main objective:

To create a website providing information on childhood cancer's late endocrine sequelae and a free MOOC (Massive Open One-line Course) dealing with post-radiation pituitary deficiency and its treatment over life and to offer on-line support and guidance to patients, their relatives and medical practitioners.

c) Secondary objectives:

To assess the usability of this website and MOOC and its efficiency in terms of percentage of patients that would be referred in Endocrinology services as well as satisfaction of users.

To improve the quality of care during transition period in order to limit as much as possible loss of follow-up.

To improve quality of information and level of health education in survivors and GPs about the long term consequences of their deficiencies.

d) Adequacy with the focus of this RFP and our departments

Our goal fits perfectly with the focus of this RFP, by trying to improve patients' and GPs' awareness and knowledge about post-radiation GHD in survivors of childhood cancer. A better knowledge of risk factors associated with the development of GHD, of which patients may be concerned by this particular condition and of the long term consequences of not being treated should favor a new patient care in endocrinology for those patients who have been lost to follow-up for many years. Our departments of adult and pediatric endocrinology are located in the same hospital and we are used to work together, particularly during the transition period where adolescents stop their treatment with GH for reassessing GH secretion and associated pituitary deficiencies. Our two departments have developed a high level of expertise in pituitary diseases and have been recognized in 2017 as a national reference center for rare pituitary disease. Moreover, also in 2017, our Center has been approved at the European level as an expert Center of the European Rare Endocrine Diseases Network (ENDO-ERN), after a call launched by the EU.

2) Current Assessment of need in target area

Progress in cancer treatment in childhood have led to major improvements in survival (1). Nowadays, more than 70% of children treated for cancer will survive. Annual incidence rate of cancer in childhood is 150 cases per million. It can be estimated that roughly 1 out of 750 young adults aged 20 to 30 is a childhood cancer survivor. Data from the US cohort have shown that among survivors, the cumulative incidence of a chronic health condition reached 73% 30 years after the cancer diagnosis, with a cumulative incidence of 42% for severe, disabling, or life-threatening conditions (2). Endocrine sequelae are among the most frequently reported complications in childhood cancer survivors, affecting 40 to 60% of these patients during adult life (2, 3, 4). According to Scandinavian registers, the cumulated risk of endocrine dysfunction might reach 43% at the age of 60 in survivors treated for cancer between the age of 5 and 9 years (5). Growth hormone deficiency (GHD) occurring after cranial irradiation involving the hypothalamo-pituitary region, is the first (and often the only) pituitary deficiency to develop during childhood (6). Endocrine pathologies notably contribute to morbidity in these patients (2). In adults, GHD is associated with altered quality of life, increased fracture risk and deleterious cardiovascular risk profile related to the increased fat mass, particularly visceral. GHD is also associated with decreased left ventricular mass. Many studies have evaluated metabolic benefit associated with GH treatment but few concerned childhood cancer survivors. One group has shown that 5-years GH therapy was associated with blood glucose decrease, improvement in lipid profile, reduction of prevalence of metabolic syndrome but no modification of left ventricular function and quality of life (7). Another study, but on a small sample of patients, showed a positive effect on bone mineral density after 2 years of treatment (8) and another demonstrated an improvement in quality of life (9).

To obtain figures about survival, compliance and treatment with GH in adulthood in France in patients treated for cancer during childhood, we analyzed a first sample of 150 patients of the cohort "EuroK" treated for cancer in childhood before 1986 in 3 sites : Institut Gustave Roussy in Villejuif, Institut Curie in Paris, and American memorial hospital in Reims. We also analyzed preliminary results of a survey performed in another sample of 263 patients treated before 2000 for their cancer in Institut Gustave Roussy and Institut Curie, during their childhood or adolescence. This allows to conclude that, in our cohort of cancer survivor patients evaluated at adulthood, around 30% of the patients have been lost to follow up, and only 5 to 13% are treated with GH on long term, because half of the patients in whom GH treatment was initiated have secondarily stopped it. The reasons of this low compliance are not well understood but certainly include defects in care organization and health professionals/patients education.

In this setting, it is interesting to note that in our survey, only 19 out of 263 patients who received GH during childhood answered "Yes" to the question "Do you have pituitary insufficiency?"...!

Studies on information needs of childhood cancer survivors have shown that, as a priority, childhood cancer survivors want information about late effects and how to deal with them (10-13). While the scientific knowledge on late effects of cancer treatments has expanded, availability of information for the lay public on late effects seems very limited in France, as compared to other countries. Only one leaflet, produced by the SFCE (The French society for childhood and adolescent cancer) clearly explains these risks and enumerates symptoms "that should alert" but nothing is written on post radiation pituitary deficiency. Other information resources are written in English and/or in a scientific language that is not readily

accessible. This contrasts with several other countries such as the US or the Netherlands, where books and websites entirely dedicated to childhood or adolescence cancer survivorship have been created.

Because the information is structured into a network of links, websites offer a more interactive and personalized way to provide information than books or booklets. Many cancer survivors turn to the Internet to find information (14). In a US study of children and adolescent cancer survivors, 95% of participants (age: 18-40) had used or wanted to use Internet sites that offer appropriate support (15). There has been a lot of innovation tools developed in this area during the past years that can be used to ensure increased comfort and overall improvement of quality of life of patients. Faced with increasingly connected patients and people with illnesses, the medical industry is continuously developing new technologies for better care. Being the precursor to telemedicine, eHealth is now developing rapidly.

3) Target Audience:

This project is first intended for adult patient survivors of childhood cancer and their relatives and general practitioners.

a) Plan for recruitment

For recruitment of our target audience, we need to make communications on medias and be referenced in Google. We have planned to create a webpage on endocrine sequelae of childhood cancer treatment and the link for the MOOC will be inserted in that page.

A website has already been created for an epidemiological study on long-term outcome in survivors of childhood cancer for the French Childhood Cancer Survivors Study (FCCSS) <http://fccss.fr/>. The scientific director of this cohort is Florent de Vathaire and the responsible for the website is Agnès Dumas, all of them are actively participating in our project. So our webpage will be referenced in their website by a link in order to redirect survivors who suffer from endocrine sequelae. Cecile Thomas-Teinturier who is the endocrine referent in the late effect committee of the French Society for Childhood and Adolescent Cancer (SFCE) will ask this society to do the same in their webpage on late effects of their website <http://sfce.fr>. This will also be proposed on the website of the French Endocrine Society www.sfendocrino.org/ (Philippe Chanson is member of the Executive Committee) and on that of French Pediatric Endocrinology and Diabetes Society www.sfedp.org/.

Communications during special sessions of the French Endocrine Society (SFE) and French Society for Pediatric Endocrinology and Diabetology (SFEDP) will be made to inform endocrinologists about this project. Special mailing and flyers will be sent to GPs, particularly those who are involved in sheltered workshops and centers for the disabled.

Flyers would be available and posters would be displayed in consultations for childhood cancer survivors and meetings organized by childhood cancer survivors associations. Information will be provided on the website of the various patients associations who already enthusiastically agree with the project.

We will send information letters with the flyers to all childhood cancer survivors who already agreed to participate to the long term follow-up cohort FCCSS and said to have received growth hormone therapy during childhood.

b) Demonstrate the scope of your target audience has a potential to impact the goal established in this proposal.

As explained above, the high number of children lost to endocrine follow-up when they reach adulthood justifies the use of every possible means for reaching our goal. We obviously have to track the patients (i.e. returning to the list of patients treated, finding if their address remains the same or by contacting their parents if they always live at the same address), finding their new address, sending them a letter which will propose a consultation if they want but overall proposing them to be informed by modern ways : network of links, websites, MOOC which offer a more interactive and personalized way of providing information than books or booklets. However, we know that a simple contact from the institution that managed their cancer during childhood for offering the program will not be sufficient in many cases (and even could be “repulsive” for some of them!). This is why our objective, in some cases, will only be to suggest them that information is available in case they are interested. We already know that many cancer survivors turn to the Internet to find information and we want them to find good information which, if they need, will lead them to come into contact with us for evaluation and treatment.

c) Who will directly benefit from the project outcomes?

This project is directly dedicated toward a subpopulation of pituitary deficient patients, those who experienced pituitary deficiency after radiation therapy for a childhood cancer and its goal is educational. But the specific module of the MOOC on GH therapy could be used also for every GH deficient patient, nurse or GP who are involved in GH therapy whatever the etiology. If this way of recruiting patients who are lost to follow-up is valuable, then our project could serve as a model for a strategy to be developed in other chronic diseases where patients are non compliant or lost to follow-up after adolescence.

4) Project Design and Methods:

a) Description of the organization and the content of the webpages on Endocrine sequelae after treatment for childhood cancer

These webpages will be included in the website of our organization (APHP Hôpitaux Paris-Sud) in link with the page dedicated to the Departments of Adult Endocrinology and Pediatric Endocrinology. These webpages will be first intended for patients and their relatives, but will also include specific resources for health care professionals such as general practitioners (GP's).

It will include internal resources on the different endocrine sequelae that can be expected after treatment for childhood cancer listed by organ i.e. pituitary, thyroid, gonads or disease i.e. growth, puberty, diabetes, obesity and osteoporosis. The text information will be provided through a search engine structure on late effects, accessible to all web-users, providing access to textual and visual information. A brief report in a language understood by the great majority will be available, as well as links to external resources such as press releases related to scientific studies and researches that we, collaborators or others have already published, information about support groups and patients associations and links to websites dealing with other late effects in survivors of childhood cancer.

The website will ask for a HON Code certification. The HONcode is the oldest and the most used code for medical and health related information available on Internet (<http://www.hon.ch/HONcode/Conduct.html>).

An e-mail address will also be offered to allow any physician (GP's, specialist) or patient who does not have a referent in endocrine sequelae to ask a question or to find a referent. The management of the e-mail address will be handled by a project manager and the involved clinicians.

A link to subscribe to the MOOC free of charge will be provided in the main website.

The site host will be our organization, in order to carry out maintenance and continuing updating. Keywords index will be defined to spotlight our webpage on Google search for the web-users. So this webpage will be permanent.

b) MOOC on post-radiation pituitary sequelae

The MOOC on post-radiation pituitary sequelae will combine videos and texts with voices on pituitary sequelae. It will be elaborated by endocrinologists and pediatric endocrinologists for medical content, supervised by academics teachers and regularly checked by patients. Their computerized design will be done by scholar engineers well trained in e-learning. It will be adapted to be viewed by every childhood cancer survivors, whatever the treatment or late effects he or she has had. For GPs who will participate to the MOOC, in order to increase its attractiveness, we will ask competent professional authority to recognise this resource for ongoing education in order to offer continuing education credits for the GPs that will complete the MOOC.

For this project, the MOOC will be first running for 6 months. But even after these 6 months, it will be available permanently on the hosting website, so every web-users can read it, but without moderator. Moreover, we could make it running for other periods of time if this tool is valuable and workable.

Registration modalities

The registration to the MOOC will be free of charge and only require a valid email address and the answer to one question "are you a patient, a relative or a GP?". This email address will be kept in a database in order to identify the participant, his answers to quiz and later to send him (her) a questionnaire for analysis of this tool efficiency.

Content of the MOOC

This MOOC aims to help to acquire knowledge on pituitary deficiency after radiation therapy, exchange informations with medical experts in this field, listen to their recommendations on appropriate investigations and follow-up and learn about GH treatment modalities.

It will be built in 4 modules, each module is independent and will be preceded and followed by a quiz, in order to test the acquired knowledge and its impact on the desire of patients to be referred -or of GPs to refer their patients- to Endocrinologists. Quiz will include 5 to 10 true or false questions in each module.

Module 1: "What is pituitary deficiency after radiation therapy?"

Its objectives are to increase knowledge on pituitary deficiencies : who is at risk after radiation therapy (which doses, what kind of radiotherapy, how long after radiation therapy...), symptoms related to each deficiency, how to diagnose them...

Module 2: "All you want to know on GH therapy"

This will be a typical training on therapeutic education with texts and photos on different devices used with GH therapy, videos of a nurse carrying out a patient's education with demonstration of an injection, and lastly patients testimonies.

Module 3: "GH therapy or not? Benefits and long term risks."

This module will explain the long term consequences of untreated GHD on cardio-vascular risk, osteoporosis, body composition, muscular strength, all risks that are also raised by cancer therapy received in childhood. Then it will explain the effects of GH therapy in preventing these risks and the appropriate follow-up. For these aims, patients testimonies and a video showing the first medical consultation after GH therapy start with questions/answers should be a good option. Lastly, it will show what is known today on the long term risks of GH therapy in the irradiated patient.

Module 4: "Why should I continue GH therapy given that I have stopped growing?"

This module is dedicated to adolescents in order to explain the effects of GH therapy other than growth. It will repeat some items from the module 3 but in a way and language that should be more attractive for adolescents (musical, BD, serious game...). A serious game is one of our preferred solutions because it can convey a message to the player in an attractive and fun way.

c) **Forum**

A forum will be available only for registred users of the MOOC. It will be moderated by a community manager who will be our junior endocrinologist. Every patient or GP participating to the MOOC can ask a medical question on post radiation pituitary sequelae, get general or individual information on medical care or who needs an endocrine evaluation or find a referent in his area.

d) **Evaluation**

The project manager will count every month the number of visits on our webpage and verify that the keywords are well referenced on Google. He will count the number of registrations on our MOOC.

The evaluation form will be based on analysis of the quiz. The quotation will be easy as the same true/false questions will be asked before and after each module, allowing a scoring of acquired knowledge for each module and each participant. As each module of the MOOC is independent, we will be able to score which module was the best appreciated, which of them was the most educational....

e) **Innovation**

Nowadays there is no educational website dealing with endocrine sequelae in survivors of childhood cancer in France. We made a Google search with different key words in French and we did not find any link. We then explored different French websites dealing with late effects after childhood cancer and the only data that we found were those written by us.

We also looked for a special educational program on GH therapy on the web. The only website providing large information on GH treatment in French is that of EliLilly. To our knowledge, based on our responsibilities in the French Endocrine Society, in the French Pediatric Endocrine Society and in the French Society for Childhood Oncology and based on our contacts with patient's associations, we are not aware of such a program in French, particularly dedicated to French-speaking patients.

5) Evaluation Design

a) **Main evaluation criteria: Feasibility, use of the website and MOOC on post-radiation pituitary sequelae.**

The satisfaction with the content, usability and design of the website for the patients will be studied by a specific questionnaire completed at the end of the training with the MOOC. The number of website visits will be counted by the project manager as well as the number of registrations to the MOOC (number of patients and GPs registrations) and the evolution in numbers followed up over time.

b) **Secondary evaluation criteria:**

Improvement in the rate of survivors who restart endocrine follow-up, who remain on GH therapy at adult age or who restart GH therapy at adult age.

To evaluate this criteria, every patient who will have participated in the MOOC will receive by email 6 and 12 months after their participation, a specific questionnaire that will be elaborated with the Inserm epidemiology team in order to know if :

they have intended to start or restart endocrine follow-up

they have actually started or restarted this follow-up

a new endocrine assessment has been done

GH therapy has been restarted if they are qualified for this treatment

A few clinical anonymous data will be recorded for statistical analysis.

The medical practionners will receive a questionnaire to know if :

They will advise their patients to undergo endocrine assessment

They will advise their patient to use GH therapy if qualified

They actually did it and in how many patients

If yes, did the patients follow their advice and how many of their patients started GH therapy?

A few clinical anonymous data on their patients will be recorded for statistical analysis.

For this part of this study we have planned to ask for prior agreement from our ethical board, if we get the funding. The preparation of this administrative file will be conducted together with the MOOC production so that the project can begin without delay as soon as the funding has been obtained.

Statistical analysis of the answers will be conducted by the epidemiology team, in terms of total numbers and percentage. If the numbers of answers allow it, the potential association with the following characteristics will be investigated: age, gender, cancer diagnosis, institutionalized individuals, educational levels and other associated medical conditions. Continuous variables will be tested with t-test and categorical variables with Chi-square. We

will use non parametric methods if necessary (Fisher's test for categorical variables and Wilcoxon test for continuous variables).

Our objective is to increase by at least 20% the number of adult patients survivors of childhood cancer evaluated in our Endocrinology clinic (or another if the patient does not live in Ile de France area and prefers to be followed somewhere else).

Improvement in the quality of care during transition period to allow absence of follow-up loss.

This item will be analysed in the same manner as the previous one but limited to the number of adolescents who will follow the course.

Our objective is to decrease by 20% the number of patients lost to follow-up during transition.

Perceived improvement in knowledge about childhood cancer late endocrine effects in survivors and medical practitioners.

This point will be addressed by the analysis of the difference in the quiz answers before and after the specific training with the MOOC. A numeric scoring for each patient/GP will be defined by the number of true answers after the MOOC lowered by the number of true answers before the MOOC.

c) Dissemination of the results

The results on the efficiency of this approach in terms of improved medical management of these patients will be broadly disseminated by scientific communications during meetings on endocrinology and/or late effects after childhood cancer, by communications in meetings of patients associations and by a scientific paper.

6) Detailed Workplan and Deliverables Schedule:

This project is intended to start as soon as the funding will be available. We anticipated that we will get the funds in November 2017. If it will be later on, then the deliverables schedule should be delayed.

- **Start** in November 2017, end in December 2019.

- **Webpage Creation** : needs our webmaster help and to write the medical content of the pages. Last quarter of 2017.

- **MOOC design phase**: needs to write the medical content and the quiz, think of the several possible ways for best approaches, select service provider that offers the best service for our needs, create the MOOC and put it on line with the creation of the associated forum. First semester of 2018.

- **Obtaining institutional review board (IRB)** and independent ethics committee (IEC) approval. Registration with the French Data protection registrar in order to save email addresses in a computed file and send questionnaires to the MOOC participant afterwards. Last quarter 2017 and first semester 2018.

- **The MOOC and the associated forum will run** for 6 months. : second semester of 2018.

- **Analysis of the results** of the MOOC associated quiz in terms of improvement of patients and GPs knowledge: first quarter of 2019.

- **Dissemination of the results** on knowledge improvement : second quarter of 2019.

- **Mailing of the questionnaires on efficiency** of the MOOC to improve medical care of patients: year 2019.
- **Analysis of the results of the questionnaires** on efficiency of the MOOC to improve medical care of patients: last quarter of 2019.
- **Dissemination of the results** on the efficacy on medical care: last quarter of 2019.

Work steps	2017	2018				2019			
	Quarters								
	4	1	2	3	4	1	2	3	4
Webpage creation									
MOOC design phase									
Obtaining legal approvals									
MOOC and forum running									
Analysis of knowledge improvement by the MOOC									
Dissemination on knowledge improvement									
Questionnaires mailing on changes in medical management of patients									
Analysis of changes in medical management of patients									
Dissemination on changes in medical management of patients									

E) References

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2) Leadership and Staff Capacity:

Our expertise includes endocrine complications of cancer treatment (radiotherapy, chemotherapy), both in adults and children. Due to this expertise, we have developed a

close relationship with Institut Gustave Roussy, the main cancer institute in France. This relationship is reinforced by the participation of one of our pediatric endocrinologists (Dr Thomas-Teinturier) to the follow-up of patients treated during childhood for cancer, to the late effect group of the SFCE and to the epidemiology research team (Inserm UMR1018). As our Reference Center for Rare Pituitary Diseases is approved by the French Ministry of Health, many patients of Ile de France region but also from many places of France and overseas territories (and also North Africa) are referred to Bicêtre hospital.

Project lead: Professor Philippe Chanson, MD

Professor of Endocrinology at Paris-Sud University and Head of the Service d'Endocrinologie et des Maladies de la Reproduction at Hôpital Bicêtre. Also head of the French Reference Center for Rare Pituitary Diseases and of the Bicêtre Center of the Endocrine European Rare Diseases Network approved by UE. He already proved by leading numerous national and international projects or clinical trials that he is able to oversee the project and ensure that tasks are accomplished as planned.

Scientific committee to define and validate medical content of the MOOC and webpage :

Doctor Cécile Thomas-Teinturier, MD, pediatric endocrinologist, Hôpital Bicêtre, France

Doctor Sylvie Salenave, MD, endocrinologist, Hôpital Bicêtre, France

Doctor Brice Fresneau, MD, pediatric oncologist, institut Gustave Roussy, Villejuif, France

Junior endocrinologist : Doctor Emmanuelle Kühn, MD, endocrinologist, hôpital Bicêtre, France

She will be responsible for writing the medical content of the website and MOOCs, studying data results of the quiz, answering questions from the GP's, tracking survivors who will return to endocrinology departments for hormonal testing, organizing one-day hospital to detect pituitary deficiencies and its consequences for those survivors who asked for it.

Endocrinologists team

Both the adult and Pediatric Endocrinology services have also doctors and nurses who developed high expertise in pituitary field due to the high number of patients referred to Bicêtre Hospital which is one of the most famous Center not only in France but also in Europe managing these patients. Not only care but also clinical research about pituitary disease have contributed to the renown of Bicêtre.

Epidemiology team : responsible for Questionnaires design and Statistical analysis of the results :

Florent de Vathaire, PhD, epidemiologist, Inserm CESP UMR1018, Villejuif, France

Agnès Dumas, PhD, social science researcher, Inserm CESP UMR1018, Villejuif, France

The team: Epidemiology of radiation, clinical epidemiology of cancer and survival is part of UMR 1018/CESP - Centre for research in epidemiology and population health. This group's work focuses on epidemiology of cancers and, more specifically, on the epidemiology of the effects of ionising radiation; the long-term iatrogenic effects of treatment of cancer and the outlook for patients treated for cancer or tumours. For several years, the group has been setting up and following cohorts of subjects exposed to very variable doses of ionising radiation. The group's main cohort is that of the French Childhood Cancer Survivors Study (FCCSS), a national cohort of 20,000 subjects treated before the year 2000 for childhood

cancer. The FCCSS is the continuation of the French contingent of the EURO2K historic cohort and is a component of the Hope-épi (Programme of Investment in the Future) project. The role of radiotherapy and chemotherapy on the outlook for children treated for solid tumours is explored by sending a self-administered questionnaire, the establishment of follow-up visits and estimation of the doses administered during radiotherapy both within and at a distance from the irradiation fields. The study of the outcome for subjects treated for cancer, in particular in childhood, has become the principal research project of the team over the last five years.

Specialized nurse for GH educational therapy

Angelique Bresson, nurse, is already responsible for all educational programs. She has a good experience in diabetic patients education and in education of patients with pituitary diseases.

H) aff Biosketches

1/ Chanson Philippe



Affiliation :

Assistance Publique-Hôpitaux de Paris, Hôpitaux Universitaires Paris-Sud, Hôpital Bicêtre, Service d'Endocrinologie et des Maladies de la Reproduction, Le Kremlin Bicêtre, 94275 France & University Paris-Sud - University Paris Saclay, Faculté de Médecine, Le Kremlin-Bicêtre, 94276 France

Phone : 33145213708 E-mail : philippe.chanson@bct.aphp.fr

Present position

Professor of Endocrinology at University Paris Sud, Head of the Service d'Endocrinologie et des Maladies de la Reproduction, Hôpital Bicêtre

Education/Training

1972-1978 Medical School : Faculté de Médecine Paris-Ouest, Paris V University.

1978- 1984 Internship in Assistance Publique-Hôpitaux de Paris, France

1984-1988 Chef de Clinique Assistant in the Department of Internal Medicine and Endocrinology at Lariboisière Hospital and Faculté de Médecine Lariboisière Saint-Louis, in Paris, France

1988-1994 Associate Professor in the Department of Internal Medicine and Endocrinology at Lariboisière Hospital and Faculté de Médecine Lariboisière Saint-Louis, in Paris, France

1996- Professor of Endocrinology at Faculté de Médecine Paris-Sud, Université Paris Sud, Paris Saclay

Educational/ teaching activities (national/international) last 5 years

1994-ong. Teaching of Endocrinology in Faculté de Médecine Paris-Sud, University Paris Sud 11, to medical students (lectures and masterclasses at the University, clinical training at the clinic and in the Service of Endocrinology)

1994-ong. Teaching to residents in Endocrinology, in the Medical Department of Bicêtre Hospital

1994- ong. Regular master courses on general endocrinology, pituitary diseases at national level for residents, for post-graduates, for CME

1994- ong. Organization and coordination of the University Diploma of Hypothalamo-Pituitary diseases, University Paris-Sud, and participation to the courses (2 weeks each year)

2012-ong. Elected Member of the National Council of Universities (section 54-04, Endocrinologie, Diabète et Maladies Métaboliques) which selects candidates for University positions available in France in Endocrinology

1994-ong. Member of PhD and MD jury (2 to 3 each year) in France, in Liège University, Belgium (n=1) and as Opponent for PhD thesis at Sahlgrenska Academy, Göteborg University, Sweden (n=1) and at Lund University, Malmö, Sweden (n=1)

2011 Organization of a Masterclass on Pituitary Diseases at Bicêtre Hospital for an international group of neuroendocrinologists from Latin America

2012 Organization of a Masterclass on Pituitary Diseases at Bicêtre Hospital for an international group of neuroendocrinologists from Algeria

2000-ong. Expert at French National Health Authority for writing of National Protocols of Diagnosis and Care for rare diseases (McCune-Albright syndrome, Cushing's syndrome, Turner syndrome, Congenital Adrenal Hyperplasia)

2010-ong. Since 2010 Editor of the 2nd edition of the book "Traité d'Endocrinologie" and Author of 16 chapters in books and of 25 review articles.

Educational activities for patients

2007-ong. Scientific Expert for Endocrinology at ORPHANET (advice, writing of information form on acromegaly available on the website of Orphanet, regular answer to patients questions on the website)

2012 Coordination of a public information website accessible for patients with acromegaly on the site of the French Society of Endocrinology: www.s fendocrino.org/acromegalie

Relevant Scientific Prizes/Functions/Funding (national/international)

1997-ong. Secretary of the "French Pituitary Club", a working group on Neuroendocrinology of the French Society of Endocrinology. Organization of bi-annual national scientific meetings (<http://www.s fendocrino.org/categorie/14>)

2009-ong. President of the "International Clinical Endocrinology Annual Meetings HP Klotz" in collaboration with French Society of Endocrinology. Organization of a yearly 2 days-meeting in Paris devoted, each year to a different topic of Endocrinology (<http://www.s fendocrino.org/categorie/17>)

2013 Member of the Program Organizing Committee /Annual Meeting Steering Committee for ICE/ENDO 2014

2014 Expert for selection of grant applications for Wellcome Trust and British Heart Foundation

2010-ong. Treasurer of European Neuroendocrine Association (ENEA)

2011-2015. Member of the Editorial Board of the Journal "Endocrine"

2011-ong. Member of the Editorial Board of the Journal "Pituitary"

2016 Expert at EMEA (London, UK)

2012 Funding by Ministry of Health (National Clinical Research Project) of a project on cardiac MRI in patients with Cushing's syndrome.

2013 Funding by Ministry of Health (National Clinical Research Project) of a project on cardiac MRI in patients with acromegaly (cofinanced by Pfizer)

1994-ong. Funding by pharmaceutical industry (Ipsen, Novartis, Pfizer) for research grants and numerous clinical trials (somatostatin analogues, GH receptor antagonists, GH receptor antisense, long acting GH, GH secretagogues...)

1994-ong. Reviewer for many journals (J Clin Endocrinol Metab, Eur J Endocrinol, Clin Endocrinol, Pituitary, Lancet Diab Endocrinol...)

2013 President of the LOC of the national meeting of the French Society of Endocrinology (Paris)

2006-2016 Cofounder of the French Reference Center for Rare Growth Endocrine Diseases approved and funded in 2006 by the French Ministry of Health

2017- ong : Head of the French Reference Center for Rare Pituitary Diseases approved and funded in 2017 by the French Ministry of Health.

2017-ong Leader of the HCP Bicêtre for Endo-ERN approved in 2017 (UE program for Rare Diseases Networks)

2005-ong. Basic research (renal effects of GH & AIP and pituitary tumorigenesis) at the lab of INSERM U1185 (Le Kremlin-Bicêtre)

2006-ong, Participation to Ercusyn (European Register on Cushing's Syndrome) (Programme of community action in the field of public health -2003-2008-)

2005-ong. Participation to the International Acromegaly Registry "Liege Acromegaly Survey" leded by Albert Beckers (Liège Belgique).

2005-ong. French Expert for the International Consensus Expert Group on Acromegaly (10 annual meetings since 2005)

2011 French expert for the International Consensus meeting "GH and IGF-I Assays, Present and Future" held in Charlottesville (North Carolina, USA)

2015 French expert for the international consensus meeting « Long-Acting GH » held in Asilomar (California, USA)

Since 2005, 70 invitations for international conferences and 38 invitations for national conferences

Publications:

249 Original Papers (80 during the last 5 years);

43 Review Papers & 60 Book Chapters (since 2000)

h-index : 55

2/ KUHN Emmanuelle

FIRST NAME:	Emmanuelle
LAST NAME:	KUHN
ACADEMIC TITLE:	Doctor
PRESENT POSITION:	Clinical Lecturer (Assistant Professor)
[REDACTED]	
DATE ISSUED:	January 2012
INSTITUTION NAME:	CHU de Bicêtre
WORK ADDRESS:	Endocrinology and reproductive diseases department 78, rue du general Leclerc 94275 Le Kremlin Bicêtre France
WORK TELEPHONE NUMBER:	+33 (0)1 45 21 37 09 (assistant)
BUSINESS E-MAIL ADDRESS:	emmanuelle.kuhn@aphp.fr

QUALIFICATIONS/PROFESSIONAL EXPERIENCE:				
Title	Date Obtained Month / Year (Chronological Order)	Name of Educational Establishment	City	Country
Assistant Clinical Head	2014-ongoing	CHU of Bicetre	BICETRE	FRANCE
POSTGRADUATE MEDICAL / OTHER PROFESSIONAL OR SPECIALIST TRAINING:				
Institution	Date Month / Year (Chronological Order)	Nature of Training/Qualification		
Hôpital Cochin	January 2012	MD		
Paris-Sud 11	2012	University Diploma of hypothalamic-pituitary pathologies		
Paris	Oct 2013	Post graduate degree in Endocrinology, Diabetes, and Metabolic diseases		
Paris-Sud 11	Oct 2014	PhD		

QUALIFICATIONS/PROFESSIONAL EXPERIENCE:		
Gothenburg University	May-June 2017	Postgraduate Course
GOOD CLINICAL PRACTICE TRAINING		
Received from:	DATE Month/Year	Nature of training
NIDA Clinical Trials Network	July 2016	Distance Learning

PREVIOUS POSITION(S) HELD & START / END DATES:			
POSITION	HOSPITAL	START DATE Month / Year (Chronological Order)	END DATE Month / Year (Chronological Order)
Resident	Paris Hospital	Nov 2006	Nov 2011
Resident	Hospital of Rouen	Jul 2006	Aug 2006

CLINICAL TRIAL EXPERIENCE:	
THERAPEUTIC AREA (Alphabetical Order)	YOUR ROLE IN STUDY (e.g. Principal Investigator, study nurse, etc)
SORTIDIAB clinical trail	sub-investigator
MPowered OOC-ACM-302 clinical trial	sub-investigator
AXELS Clinical trial	sub-investigator

NUMBER OF PUBLICATIONS: 11 original publications and 9 communications

3/ Agnes DUMAS

BIOGRAPHICAL SKETCH

NAME: Agnes DUMAS

eRA COMMONS USER NAME (credential, e.g., agency login):

POSITION TITLE: Researcher (contractual)

EDUCATION/TRAINING

INSTITUTION AND LOCATION	DEGREE	Completion Date MM/YYYY	FIELD OF STUDY
Sciences Po Paris	MA	09/2003	Political sciences
Université Paris Descartes	MA	07/2006	Demography
Université Paris Descartes	PhD	02/2011	Sociology

Personal Statement

I am a medical sociologist with a background in both political sciences and demography. My research interest lies in health disparities. I began to work on this issue by conducting studies on the pregnancy outcomes of substance users (PhD). During my PhD, I earned a fellowship travel grant and I spent a year in CUNY (City University of New York) where I did a comparative study on the French/Us policies regarding substance during pregnancy.

I have been working since 2011 at Gustave Roussy as a post-doctoral researcher (contractual researcher), first within the Unit of Research in Social and Human Sciences and since 2015 in the INSERM Unit (Center for research in epidemiology and population health - U1018, Cancer & radiation team). My research focuses on cancer survivorship after childhood and breast cancer, and I use both quantitative and qualitative methods to conduct studies to investigate the social impact of cancer. I am also involved in two intervention studies on cancer screening (breast and colorectal).

In addition, I teach the sociology of health and quantitative methods to graduate students in two universities (Paris Descartes, Sociology Department; and Paris Diderot, Medicine Department).

Positions and Honors

Positions and Employment

2016-present Assistant professor (*enseignant vacataire*), Paris Diderot University, Medicine Department,

2016-present Assistant professor, Paris Descartes University, Sociology Department,

2015-Present Postdoctoral Researcher, Gustave Roussy Institute, Center for research in Epidemiology and Population Health (INSERM U1018)

2011-2014 Postdoctoral Researcher, Gustave Roussy Institute, Social and Human Sciences Research Unit

2009-2010 Visiting research scholar, CUNY (City University of New-York), Sociology Department
2007-2010 PhD fellow, Paris Descartes University
2007-2010 Teaching fellow (*Moniteur*) Paris Descartes University, Sociology department
2005 Research analyst, CPAM (French health insurance agency),
2005 Research assistant, CNRS (National Centre for Scientific Research)
2003-2004 Research analyst Foch Hospital, Association F3A (Non-profit organization)

Honors

2003 First Class Honors, MA Paris Descartes
2003 PhD Fellowship of the French Ministry of Education and Research

Contribution to Science

Cancer survivorship

Dumas A, Allodji R, Fresneau B, Valteau-Couanet D, El-Fayech C, Pacquement H, et al. The right to be forgotten: a change in access to insurance and loans after childhood cancer? *J Cancer Surviv.* 2017 (in press).

Demoor-Goldschmidt C, Drui D, Doutriaux I, Michel G, Auquier P, Dumas A, et al. A French national breast and thyroid cancer screening programme for survivors of childhood, adolescent and young adult (CAYA) cancers - DeNaCaPST programme. *BMC Cancer.* 2017;17(1):326.

Dumas A, De Vathaire F, Vassal G. Access to loan-related insurance for French cancer survivors. *Lancet Oncology.* 2016;17(10):1354-6.

Pourtau L, Dumas A., Amiel P. [Cancer survivors]. *Temporalités.* 2011 (13).

Social well-being and quality of life after a pediatric illness

Mellerio H, Dumas A, Guilmin-Crepon S, Loirat C, Levy-Marchal C, Audard V, et al. [Well-being in adulthood of patients with chronic conditions in childhood: The GEDEPAC-2 questionnaire]. *Rev Epidemiol Sante Publique.* 2017;65(2):137-48.

Dumas A., Berger C., Auquier P., Michel G., Fresneau B., Allodji R.S., Haddy N., Rubino C., Vassal G., Valteau-Couanet D., Thouvenin-Doulet S., Casagrande L., Pacquement H., El-Fayech C., Oberlin O., Guibout C., de Vathaire F. Educational and occupational outcomes of childhood cancer survivors 30 years after diagnosis. *British Journal of Cancer.* 2016; 114(9):1060-8.

Dumas, A., Berger, C., Auquier, P., Michel, G., Vassal, G., Valteau-Couanet, D., Fresneau, B., Thouvenin-Doulet, S., Casagrande, L., Pacquement, H., El-Fayech, C., Oberlin, O., Guibout, C., De Vathaire, F., 2016. Trajectoires scolaires après un cancer pédiatrique : une contribution à l'hypothèse de la sélection par la santé. *Revue d'Épidémiologie et de Santé Publique*, 64S, p. S109.

Late effects of childhood cancer

Allodji R., Diallo I., El-Fayech C., Kahlouche A., Dumas A., Schwartz B., Oberlin O., Benadjaoud M., Labbé M, Jackson A., Bullet J., Rubino C., Haddy N., De Vathaire F. Radiation dose to the eyes in the risk of cataract after non-retinoblastoma solid childhood cancers. *JAMA Ophthalmology*, 2016; 134(4):390-7.

Breast cancer screening

Ouédraogo S., Dabakuyo-Yonli T.S., Roussot A., Dialla P.O., Pornet C., Poillot M.-L., Soler-Michel P., Sarlin N., Lunaud P., Desmidt P., Paré E., Mathis C., Rymzhanova R., Kuntz-Huon J., Exbrayat C., Bataillard A., Régnier V., Kalecinski J., Quantin C., Dumas A., Gentil J., Amiel P., Chauvin F., Dancourt V., Arveux P. [Breast cancer screening in thirteen French departments]. *Bulletin du Cancer* 2015; 102(2): 126-138.

Kalecinski J., Ouédraogo S., Dabakuyo-Yonli T.S., Dumas A., Chauvin F., Arveux P. [Organized or individual breast cancer screening: what motivates women?]. *Santé publique*. 2015; 27 (2): 213-220.

Ouédraogo S., Dabakuyo-Yonli S., Amiel P., Dancourt V., Dumas A., Arveux P. Breast cancer screening programmes: challenging the coexistence with opportunistic mammography. *Patient Education and Counseling*. 2014; 97(3): 410-417.

Substance use during pregnancy

Dumas A., Toutain S., Lejeune C., Simmat-Durand L. Alcohol drinking during pregnancy or breast feeding: a French national survey. *Journal of Women's Health* 2017 (in press).

Dumas A., Lejeune C., Simmat-Durand L. [Tobacco, alcohol, marijuana and pregnancy: which women are at risk?]. *Santé publique*. 2014; 26(5): 603-612.

Dumas A., Simmat-Durand L., Lejeune C. [Pregnancy and substance use in France: A literature review.]. *Journal de gynécologie obstétrique et de biologie de la reproduction*. 2014; 43(9): 649-656.

Dumas A., Toutain S., Simmat-Durand L. The French Paradox: Forbidding Alcohol during Pregnancy, but Making an Exception for Wine. In Hoffman J.D. (dir) *Pregnancy and Alcohol Consumption*. Nova Science Publishers. New York : 2010. p. 245–61.

Dumas A, Simmat-Durand L, Lejeune C. Représentations du risque alcool chez les personnels de l'obstétrique. In Simmat-Durand L. *Grossesses avec drogues. Entre médecine et sciences sociales*. L'Harmattan. Paris: 2009. p. 67–87.

Dumas A., Lejeune C., Simmat-Durand L., Crenn-Hébert C., Mandelbrot L. [Pregnancy and psychoactive substances: prevalence study based on the declared consumption]. *Journal de gynécologie obstétrique et de biologie de la reproduction*. 2008; 37(8): 770-778.

Dumas A., Lejeune C., Simmat-Durand L., Bonnaire C., Michaud P., Hillaire S. Prévention du syndrome d'alcoolisation foetale (SAF): Pratiques et représentations des professionnels de la périnatalité. *Alcoologie et addictologie*. 2006; 28(4): 311–316.

List of Published Work in: <http://www.ncbi.nlm.nih.gov/pubmed/?term=Dumas+A>

Research Support

Ongoing Research Support

INCA (French NCI) – Call for project: Social Sciences and Epidemiology

Role: Principal Investigator

ALLIANCE: (ALLiance between Institutions, Adults, pareNts, Clinicians and rEsearchers to improve access to information after childhood, adolescent or young adult cancer)

The main aim of this study is to identify supportive care needs and preferences among CAYA cancer survivors, using both a quantitative and qualitative approach. A secondary aim is to design a website and e-tools that will improve knowledge transfer about childhood cancer late effects, on the basis of a collective consultation with survivors, clinicians, researchers and institutions.

ANR (French national research agency) - “Investissement d’avenir” (*“Investing for the Future”*)

Role: Investigator

CANTO (PI: Fabrice Andre, Gustave Roussy Institute): A multicentric prospective cohort of 12 000 breast cancer survivors investigating chronic treatment toxicities. I am co-leader for the WP investigating psychosocial impact of cancer and toxic events related to treatments.

INCA (French NCI) – Call for project: Intervention research

Role – Investigator

DeCLIC (PI: Zoe Vaillant, Paris-Nanterre University):

The intervention consists in implementing a process to produce, exchange and share knowledge about social and spatial inequalities in breast cancer screening and their local combinations of determinants in different cities of the Paris area. This knowledge translation process is built on a strong partnership between different relevant stakeholders that usually are separated: academic researchers and students, public health practitioners and decision makers as local representatives. I provided scientific support in political science all along the project and I am writing an article on the results.

Fondation de France

Role: Investigator

MICRO-QoL (PI: Sandrine Dabayuko, Centre GF Leclerc)

This study aims at assessing quality of life and psychosocial impact of cancer in thyroid cancer survivors. I designed a part of the questionnaires and I will provide scientific support for the analyses.

Fondation ARC

Role – Investigator

DENACAPST (PI: Demoor-Goldschmidt, INSERM U1018). This project aims at evaluating the feasibility and the effectiveness of a national screening program for breast and thyroid second cancers for childhood cancer survivors. I designed a part of the questionnaires and I will provide scientific support for the analyses.

Completed Research Support

Ligue Nationale contre le cancer – Social and Human Sciences call for project: Role – Investigator

Survican (PI: Philippe Amiel, Gustave Roussy Institute): A qualitative study investigating the psychosocial consequences of a childhood cancer in adult life (80 interviews with a randomly selected sample of participants of the FCCSS study, a 2 400 adult survivors of childhood cancer cohort in France.

Ligue Nationale contre le cancer – Social and Human Sciences call for project

RSI Régime social des Indépendants (French Social Security scheme for the self-employed workers)

Role – Investigator

Indepcan (PI: Philippe Amiel, Gustave Roussy Institute): A study on the socioeconomic impact of cancer on self-employed workers: a mixed method research with 1) a qualitative part: 91 interviews with 2 years survivors independent workers 2) a quantitative part: a

complementary analysis of self-employed workers participating in VICAN2, a national survey (Inserm/Inca) among 4 000 French survivors. I conducted interviews, I designed questionnaires and I analyzed them.

DGS (French ministry of health)

Role: Principal Investigator

ESPAG – A cross-sectional survey was carried out by telephone among a nationally representative sample of pregnant and postpartum women. Frequency of alcohol use and binge drinking were retrospectively measured according to distinct time periods.

4/ Florent de Vathaire

ADDRESS

Office :

Institut National de la Santé et de la Recherche Médicale.
Center for Research in Epidemiology and Population Health, U1018
Radiation Epidemiology Group
Rue Camille Desmoulins, 94805 Villejuif, Cedex, France.
Phone : +33142115457 Fax : (33) (1) 42 11 53 15
Email : florent.devathaire@gustaveroussy.fr

EDUCATION

1981 Master of Biomathematics and Biostatistics, University Paris VII, Paris.
1984: Ph.D. of Ecology, Ecole Pratique des Hautes Etudes, Paris.
1984 : Ph.D. of Biomathematics and Biostatistics, University Paris VII, Paris.
1991 : Master of Radiobiology and Radiopathology, University Paris XI, Paris.
1998 : "Habilitation à Diriger les Recherches". University Paris XI, Paris.

PROFESSIONAL EXPERIENCE

1981 : Visiting Research Fellow, Danish Biliarzasis Laboratory, Copenhagen. Automatic classification of snails vectors of schistosomiasis using gel electrophoretic techniques.
1981-1984 : Secondary school teacher.
1984-1997 Consultant in biostatistics. Experience with more than 10 drug companies and with 3 CROs.
1984-1986 Lecturer on statistical methods for clinical research. C.E.S.A.M. University Paris XI.
1984-1989 : Biostatistician, Department of Biostatistics and Epidemiology, Institute Gustave Roussy: Analysis of phase I, II, III and IV clinical trials.
1989-1999: "Chargé de Recherches". National Institute of Health and Medical Research.
1991-now Lecturer in Epidemiology. Graduate Diploma "Biological Effects of Ionizing Radiation and Radiopathology" University of Paris XI.
1995-1998 Statistician consultant for the French "Agence du Médicament".
1995-2004 Member of the Scientific Committee of the "Office de Protection Contre les Radiations Ionisantes" (OPRI).

1997-2009 Lecturer in Epidemiology. Graduate Diploma "Radiodiagnostic île de France " Univ Paris V.
1997-now Manager of the CRO "ECOSTAT". Experience with 16 drug companies
1997 Lecturer in Epidemiology. Graduate Diploma "Epidémiologie et Santé Publique " University of Paris V.
1998-2004 Statistician consultant at the AFFSSAPS.
1999-now "Directeur de Recherches" at INSERM.
1999-2006 Member of the "Conseil Supérieur d'Hygiène Publique de France".
2004-2009 Director of the Unit 605 INSERM "Cancer Epidemiology : Radiocarcinogenese and iatrogenic effects of cancer treatments"
2009 Senior Visitor. Radiation Branch, National Cancer Institute, NIH, Bethesda, USA.
2010-Now Director of the Radiation Epidemiology Group, U1018 INSERM.
Avril 2017 200 original publications referenced in Pubmed (H-factor 41)

AREAS OF INTEREST

Cancer epidemiology : risk factors, clinical epidemiology, pediatric oncology, late effects of cancer treatments.

Radiation epidemiology : low doses, high doses due to radiation therapy, dose-response modifiers, biomarkers,

Biostatistics

5/ SALENAVE Sylvie



sylvie.salenave@aphp.fr



**Service d'Endocrinologie et des Maladies
la Reproduction
CHU Bicêtre
78 avenue du Général Leclerc
94270 Le Kremlin-Bicêtre
Tel +33 145213398**

Qualifications

2009- 2017 : Praticien hospitalier des Hôpitaux de Paris CHU Bicêtre University Paris Sud

2008-2009 : Attaché temps plein des Hôpitaux de Paris University Paris Sud

2006-2008: Praticien Hospitalier Contractuel University Paris Sud

2002- 2006 : PhD Service d'Endocrinologie et des Maladies de la Reproduction
CHU Bicêtre University Paris Sud

2005 University Diploma CESAM Statistique, modules méthodologie statistique et statistique en recherche clinique University Paris VI

2001: Master Endocrinologie et Interaction Cellulaires University Paris Sud

1998- 2002 Residency

1991 First Year of of medicine school

1990 Scientific baccalaureate

Publications

Chanson P, Salenave S. Diabetes insipidus and pregnancy. Ann Endocrinol (Paris). 2016 Jun;77(2)

Briet C, Salenave S, Bonneville JF, Laws ER, Chanson P. [Pituitary Apoplexy](#). Endocr Rev. 2015 Dec;36(6):622-45. doi: 10.1210/er.2015-1042. Review.

Chanson P, Raverot G, Castinetti F, Cortet-Rudelli C, Galland F, Salenave S; French Endocrinology Society non-functioning pituitary adenoma work-group.. [Management of clinically non-functioning pituitary adenoma](#).Ann Endocrinol (Paris). 2015

Thomas-Teinturier C, Salenave S. [\[Endocrine sequelae after treatment of pediatric cancer: From childhood to adulthood\]](#). Bull Cancer. 2015 Jul-Aug;102(7-8):612-21. doi: 10.1016/j.bulcan.2015.03.013. Review. French.

Briet C, Salenave S, Chanson P. Pituitary apoplexy. Endocrinol Metab Clin North Am. 2015

Salenave S, Ancelle D, Bahougne T, Raverot G, Kamenický P, Bouligand J, Guiochon-Mantel A, Linglart A, Souchon PF, Nicolino M, Young J, Borson-Chazot F, Delemer B, Chanson P.

[Macroprolactinomas in children and adolescents: factors associated with the response to treatment in 77 patients.](#) J Clin Endocrinol Metab. 2015

Salenave S, Bernard V, Do Cao C, Guignat L, Bachelot A, Leboulleux S, Droumaguet C, Bry-Gaillard H, Pierre P, Crinière L, Santulli P, Touraine P, Chanson P, Schlumberger M, Maiter D, Baudin E, Young J. Ovarian macrocysts and gonadotrope-ovarian axis disruption in premenopausal women receiving mitotane for adrenocortical carcinoma or Cushing's disease. Eur J Endocrinol. 2015

Chanson P, Salenave S, Kamenicky P. Acromegaly Handb Clin Neurol. 2014;124:197-219. doi: 10.1016/B978-0-444-59602-4.00014-9. Review.

Salenave S, Boyce AM, Collins MT, Chanson P. [Acromegaly and McCune-Albright syndrome.](#) J Clin Endocrinol Metab. 2014 J

□ Gaujoux S, Salenave S, Ronot M, Rangheard AS, Cros J, Belghiti J, Sauvanet A, Ruzsniwski P, Chanson P. [Hepatobiliary and Pancreatic neoplasms in patients with McCune-Albright syndrome.](#) J Clin Endocrinol Metab. 2014

Salenave S, Trabado S, Maione L, Brailly-Tabard S, Young J. [Male acquired hypogonadotropic hypogonadism: diagnosis and treatment.](#) Ann Endocrinol (Paris). 2012

Chanson P, Salenave S. Treatment of neurogenic diabetes insipidus. Ann Endocrinol (Paris). 2011 Dec;72(6):496-9. Epub 2011 Nov 8.

Chanson P, Salenave S. Metabolic syndrome in Cushing's syndrome. Neuroendocrinology. 2010;92 Suppl 1:96-101. Epub 2010 Sep 10

Grynberg M, Salenave S, Young J, Chanson P. Female gonadal function before and after treatment of acromegaly. J Clin Endocrinol Metab. 2010 Oct;95(10):4518-25. Epub 2010 Jul 21.

Chanson P, Salenave S, Young J. Ovarian dysfunction by activating mutation of GS alpha: McCune-Albright syndrome as a model. Ann Endocrinol (Paris). 2010 May;71(3):210-3. Epub 2010 Apr 2

Chanson P, Salenave S, Kamenicky P, Cazabat L, Young J. Pituitary tumours: acromegaly. Best Pract Res Clin Endocrinol Metab. 2009 Oct;23(5):555-74. Review.

Salenave S, Chanson P, Bry H, Pugeat M, Cabrol S, Carel JC, Murat A, Lecomte P, Brailly S, Dode C, Young J. Kallmann's syndrome: a comparison of the reproductive phenotypes in men carrying KAL1 and FGFR1/KAL2 mutations. J Clin Endocrinol Metab. 2008 Mar;93(3):758-63. Epub 2007 Dec 26.

Chanson P, Salenave S. Acromegaly. Orphanet J Rare Dis. 2008 Jun 25;3:17. Review.

Chanson P, Salenave S [rhGH replacement therapy in adults]. Ann Endocrinol (Paris). 2007 Sep;68(4):231-6. Epub 2007 Aug 8. Review. French.

Philippe Chanson, Sylvie Salenave, Philippe Orcel. Mc Cune-Albright in adulthood. Pediatric Endocrinology Reviews 2007, 4, suppl July 2007, 453-463

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Chanson P, Salenave S. Diagnosis and treatment of pituitary adenomas. *Minerva Endocrinol.* 2004 Dec;29(4):241-75. Review.

BIOGRAPHICAL SKETCH6/ **THOMAS-TEINTURIER Cécile**

eRA COMMONS USER NAME (credential, e.g., agency login):

POSITION TITLE: medical doctor

EDUCATION/TRAINING

INSTITUTION AND LOCATION	DEGREE (if applicable)	Completion Date MM/YYYY	FIELD OF STUDY
Certificate of statistics applied to medicine, clinical research option Certificate of advanced studies in Human Genetics Certificate of advanced studies in Human Biology Hematology Master's degree in Human Genetics (Paris VI) Residency in Pediatrics, Hospitals of Paris Specialized degree in Pediatrics (Paris) Doctorate degree in Medicine Former Head of clinic of the Universities, Assistant of the Hospitals of Paris	 M2 MD	1986 1987 1987 1991 1984-1990 1990 1990 1991-1994	

A. Personal Statement

I am a Medical Doctor, Hospital practitioner, working in Pediatric Endocrinology at AP-HP since 1993.

My research interest lies in endocrine sequelae after childhood cancer, growth, puberty and pituitary disease.

In addition, I am a researcher in Epidemiology (INSERM U1018, Villejuif, France), main topic : Endocrine sequelae after treatment for cancer in childhood since 2009.

**B. Positions and Honors**

Hospital practitioner, pediatrics, AP-HP hospital Saint Vincent de Paul, Paris, 2007-2011

Hospital practitioner, AP-HP hospital Bicêtre 2011-og

Researcher in Epidemiology (Inserm, Center for research in epidemiology and population health - U1018, Cancer & radiation team) 2009-og

C. Contributions to Science

1. El-Fayech C, Haddy N, Allodji RS, Veres C, Diop F, Kahlouche A, Llanas D, Jackson A, Rubino C, Guibout C, Pacquement H, Oberlin O, **Thomas-Teinturier C**, Scarabin PY, Chavaudra J, Lefkopoulos D, Giroud M, Bejot Y, Bernier V, Carrie C, Diallo I, de Vathaire F. Cerebrovascular Diseases in Childhood Cancer Survivors: Role of the Radiation Dose to Willis Circle Arteries. *Int J Radiat Oncol Biol Phys*. 2017 Feb 1;97(2):278-286
2. **Thomas-Teinturier C**, Pereda A, Garin I, Diez-Lopez I, Linglart A, Silve C, de Nanclares GP. Report of two novel mutations in PTHLH associated with brachydactyly type E and literature review. *Am J Med Genet A*. 2016 Mar;170(3):734-42.
3. Servitzoglou M, De Vathaire F, Oberlin O, Patte C, **Thomas-Teinturier C**. Dose-Effect Relationship of Alkylating Agents on Testicular Function in Male Survivors of Childhood Lymphoma. *Pediatr Hematol Oncol*. 2015;32(8):613-23.
4. de Vathaire F, Haddy N, Allodji RS, Hawkins M, Guibout C, El-Fayech C, **Teinturier C**, Oberlin O, Pacquement H, Diop F, Kalhouche A, Benadjaoud M, Winter D, Jackson A, Bezin Mai-Quynh G, Benabdennebi A, Llanas D, Veres C, Munzer M, Nguyen TD, Bondiau PY, Berchery D, Laprie A, Deutsch E, Lefkopoulos D, Schlumberger M, Diallo I, Rubino C. Thyroid Radiation Dose and Other Risk Factors of Thyroid Carcinoma Following Childhood Cancer. *J Clin Endocrinol Metab*. 2015 Nov;100(11):4282-90.
5. **Thomas-Teinturier C**, Salenave S. Endocrine sequelae after treatment of pediatric cancer: From childhood to adulthood. *Bull Cancer*. 2015 Jul-Aug;102(7-8):612-21.
6. Rousset-Jablonski C, Giscard d'Estaing S, Bernier V, Lornage J, **Thomas-Teinturier C**, Aubier F, Faure-Contier C. Gonadal function after treatment for a childhood or adolescent cancer. *Bull Cancer*. 2015 Jul-Aug;102(7-8):602-11.
7. **Thomas-Teinturier C**, Allodji RS, Svetlova E, Frey MA, Oberlin O, Millischer AE, Epelboin S, Decanter C, Pacquement H, Tabone MD, Sudour-Bonnange H, Baruchel A, Lahlou N, De Vathaire F. Ovarian reserve after treatment with alkylating agents during childhood. *Hum Reprod*. 2015 Jun;30(6):1437-46.
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9. **Thomas-Teinturier C**, El Fayech C, Oberlin O, Pacquement H, Haddy N, Labbé M, Veres C, Guibout C, Diallo I, De Vathaire F. Age at menopause and its influencing factors in a cohort of survivors of childhood cancer: earlier but rarely premature. *Hum Reprod*. 2013; 28(2):488-95.
10. de Vathaire F, El-Fayech C, Ben Ayed FF, Haddy N, Guibout C, Winter D, **Thomas-Teinturier C**, Veres C, Jackson A, Pacquement H, Schlumberger M, Hawkins M, Diallo I, Oberlin O. Radiation dose to the pancreas and risk of diabetes mellitus in childhood cancer survivors: a retrospective cohort study. *Lancet Oncol*. 2012; 13(10):1002-10.
11. Haddy N, El-Fayech C, Guibout C, Adjadj E, **Thomas-Teinturier C**, Oberlin O, Veres C, Pacquement H, Jackson A, Munzer M, N'Guyen TD, Bondiau PY, Berchery D, Laprie A, Bridier A, Lefkopoulos D, Schlumberger M, Rubino C, Diallo I, de Vathaire F. Thyroid adenomas after solid cancer in childhood. *Int J Radiat Oncol Biol Phys*. 2012; 84 (2):e209-15.
12. Haddy N, Mousannif A, Tukenova M, Guibout C, Grill J, Dhermain F, Pacquement H, Oberlin O, El-Fayech C, Rubino C, **Thomas-Teinturier C**, Le-Deley MC, Hawkins M, Winter D,

- Chavaudra J, Diallo I, de Vathaire F. Relationship between the brain radiation dose for the treatment of childhood cancer and the risk of long-term cerebrovascular mortality. *Brain*. 2011; 134(Pt 5):1362-72.
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14. Rottembourg D, Linglart A, Adamsbaum C, Lahlou N, **Teinturier C**, Bougnères P, Carel JC. Gonadotrophic status in adolescents with pituitary stalk interruption syndrome. *Clin Endocrinol (Oxf)*. 2008; 69(1):105-11.
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16. Chalard F, Ferey S, **Teinturier C**, Kalifa G. Aortic dilatation in Turner syndrome: the role of MRI in early recognition. *Pediatr Radiol*. 2005 Mar; 35(3):323-6.
17. Dos Santos C, Essioux L, **Teinturier C**, Tauber M, Goffin V, Bougnères P. A common polymorphism of the growth hormone receptor is associated with increased responsiveness to growth hormone. *Nat Genet*. 2004 Jul; 36(7):720-4.
18. **Teinturier C**, Vallette S, Adamsbaum C et al. Pseudotumor of the pituitary due to PROP-1 deletion. *J Pediatr Endocrinol Metab* 2002, 15 : 95-101.
19. Carel JC, Lahlou N, Jaramillo O, Montauban V, **Teinturier C**, Colle M, Lucas C, Chaussain JL. Treatment of central precocious puberty by subcutaneous injections of leuporelin 3-month depot (11.25 mg). *J Clin Endocrinol Metab*. 2002; 87(9):4111-6.
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21. Vallette-Kasic S, Barlier A, **Teinturier C** et al. PROP1 gene screening in patients with multiple pituitary hormone deficiency reveals two sites of hypermutability and a high incidence of corticotroph deficiency. *J Clin Endocrinol Metab* 2001, 86 : 4529-35.
22. **Teinturier C**, Pauchard MS, Brugières L et al. Clinical and prognostic aspects of adrenocortical neoplasms in childhood. *Med Pediatr Oncol* 1999, 32: 106-11.
23. Coutant R, Pein F, Adamsbaum C, Oberlin O, Dubousset J, Guinebretière JM, **Teinturier C**, Bougnères PF. Prognosis of children with malignant pheochromocytoma. Report of 2 cases and review of the literature. *Horm Res*. 1999; 52(3):145-9.
24. Bouvattier C, Coste J, Rodrigue D, **Teinturier C**, Carel JC, Chaussain JL, Bougnères PF. Lack of effect of GnRH agonists on final height in girls with advanced puberty: a randomized long-term pilot study. *J Clin Endocrinol Metab*. 1999 Oct; 84(10):3575-8.
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26. Duquesnoy P, Roy A, Dastot F, Ghali I, **Teinturier C**, Netchine I, Cacheux V, Hafez M, Salah N, Chaussain JL, Goossens M, Bougnères P, Amselem S. Human Prop-1: cloning, mapping, genomic structure. Mutations in familial combined pituitary hormone deficiency. *FEBS Lett*. 1998 Oct 23; 437(3):216-20.

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29. **Teinturier C**, Gelez J, Flamant F et al. Pure dysgerminoma of the ovary in childhood: treatment results and sequelae. *Med Pediatr Oncol* 1994, 23: 1-7.
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31. **Teinturier C**, Danglot G, Slim R et al. The neurofibromatosis 1 gene transcripts expressed in peripheral nerve and neurofibromas bear the additional exon located in the GAP domain. *Biochem Biophys Res Commun* 1992, 188: 851-57.

D. Additional Information: Research Support and/or Scholastic Performance

Ongoing Research Support

Ligue nationale contre le cancer – Call for project: children and adolescents 2015

Role: Principal Investigator

OVALKYL-Y5: Evolution of ovarian reserve after treatment with alkylating agents for childhood cancer.

PHRC INCA (French NCI) - Call for project 2014

Role: coordinating investigator

PRESOV: Assessment of the effect of a cotreatment with GnRH analogs on the ovarian reserve in adolescents and young women treated with alkylating agents for cancer.

Completed Research Support

Ligue Nationale contre le cancer – Call for project: Adolescents and cancer 2008

Role: Principal Investigator

OVALKYL: Assessment of ovarian function after treatment with alkylating agents during childhood.

EDF (Electricité de France) – Call for project : Epidemiology and radioprotection 2013

Influence of uterine radiation dose on pregnancy outcome and offspring in female survivors of childhood cancer.

EDF (Electricité de France) – Call for project : Epidemiology and radioprotection 2012

Influence of growth hormone therapy in the occurrence of second neoplasm in survivors of childhood cancer.

EDF (Electricité de France) – Call for project : Epidemiology and radioprotection 2011

Factors affecting age at menopause after treatment for childhood cancer.