

---

# OUR 2018 ACTIVITIES



Recognized as a public-interest organization since 2015

## EDITORIAL

While 2017 was a year of reorganization for the foundation and its priorities, **2018 focused on key programs, which we co-initiated, coordinated and completed with our ecosystem.**

2018 offered a wealth of insights, opportunities to meet new partners, as well as numerous exciting challenges and projects. Our foundation truly took off, supporting research beyond French borders, opening up our Scientific Grand Prize to international candidates and creating new PhD and master studentships to broaden their expertise.

We are also happy with the progress made by our flagship project, the Hearing Institute known as Institut de l'Audition, an interdisciplinary center for basic, translational and clinical research in Auditory Neurosciences which will open its doors at the end of 2019.

The Hearing Institute provides an extraordinary opportunity for French and international researchers to accelerate the development of new therapeutic solutions by organizing a network of clinical centers.

To improve everyday life for people with hearing loss, the foundation has teamed up with experts in the field to make tangible progress, launching a school for the parents of children with hearing loss, a theater program for schools, a pilot study to make university courses accessible, and so on. These are high-profile programs we will need to promote and disseminate with our partners to contribute to equal opportunities and a better quality of life for all.

We are convinced that by working together, making every effort count and enabling every action to be part of the solution, we will find the right solutions for people to embrace their differences and enjoy life in their own ways.

Let's keep listening to life!

**Karine Rossignol,**  
Managing Director,  
Fondation Pour  
l'Audition



# INSTITUT DE L'AUDITION

2018 was a critical year, as it marked a new key partnership with Institut Pasteur to secure the future activities of the Institut de l'Audition's basic research.

The Institut de l'Audition's clinical research will be set up with the Paris hospital system known as AP-HP. This will ensure a continuum of excellence between the scientific teams directed by Christine

Petit and the network of clinical research centers for audiology nationwide.

**2019 will be a major year for Hearing Sciences: in the autumn, the institute will finally open its doors to the numerous researchers and clinicians who are working to advance basic and translational research for the benefit of all.**



# COMMUNICATION

2018 saw the first official public speaking of Fondation Pour l'Audition at its scientific awards ceremony in Paris on November 15.

At the event, Fondation Pour l'Audition presented its business, scientific and charity partners with its different projects to support research, raise public awareness and improve everyday life for people with hearing loss.

In addition, Fondation Pour l'Audition created a new digital environment with the latest version of the [foundationpurlaudition.org](http://foundationpurlaudition.org) website.

**The aim was to turn this "brochure site" into a leading platform on hearing health that would be informative, participative and a unifying force in the hearing community:**

**Informative**, because our site offers all the latest news on hearing health and hearing loss, thanks to our scientific, institutional and technological review

**Participative**, because it is now possible to submit testimonials to be posted in the editorial section

And **a unifying force** because news from different members of the ecosystem are regularly highlighted in dedicated sections, such as the hearing community wall.



# FOR RESEARCH

---

Fondation Pour l'Audition aims to accelerate research and innovation for hearing loss. Different types of funding are offered annually to help train future French talents to research and promote scientific and medical excellence.

Every submitted research project is reviewed thoroughly and independently by the foundation's Scientific Committee, chaired by Professor Karen B. Avraham, vice dean of the School of Medicine at Tel Aviv University in Israel.

---

## OUR SUPPORT FOR RESEARCH LABORATORIES IN 2018

Four research projects were selected by the foundation's Scientific Committee:

> **"COVARY: Circuits for Opposite Valences learning in Auditory cortex studied by inference of plastic connectivity"**

led by Dr. Jean-François Léger and Dr. Rémi Monasson of ENS Paris, who will explore brain plasticity during learning in mice and map neural networks in the brain's auditory area

> **"Deficit in the iron-binding protein Ftl1 reveals a new mechanism of hearing loss"**

led by Dr. Régis Nouvian at the Institute for Neurosciences of Montpellier, aiming to study the role of the Ftl1 protein in the inner ear and its role in hearing disorders in mice.

> **"Contribution of synaptic and neuronal mechanisms to a cerebellar representation of auditory sequences"**

led by Dr. David DiGregorio of Institut Pasteur in Paris, aiming to explain the essential cellular mechanisms in the cerebellum of mice for perceiving pitch

> **"Analysis of long-range regulation of DFNB1 locus implicated in nonsyndromic hearing impairment"**

led by Professor Claude Férec at the University of Western Brittany in Brest, aiming to identify the regulatory regions of the DFNB1 DNA locus involved in nonsyndromic hearing loss.



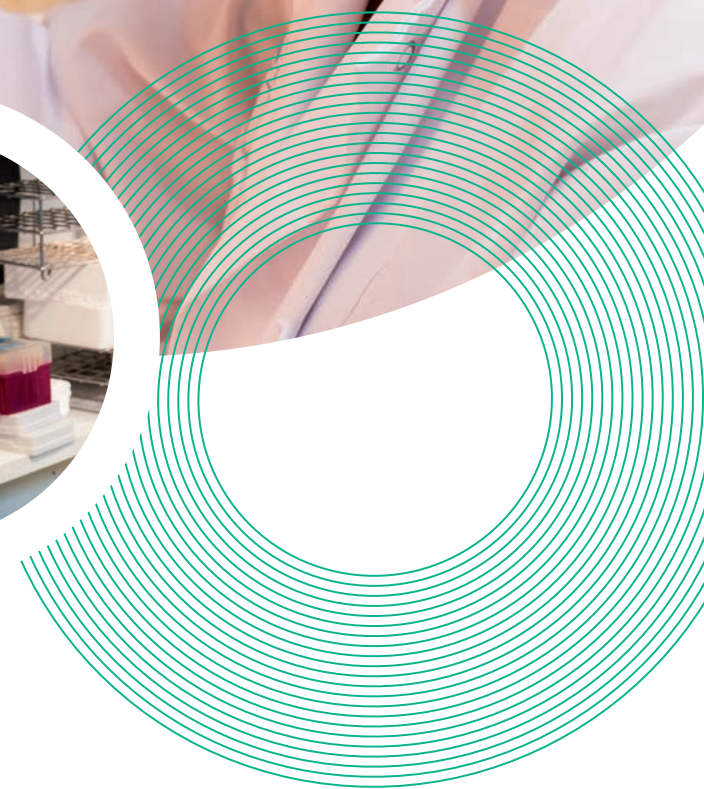
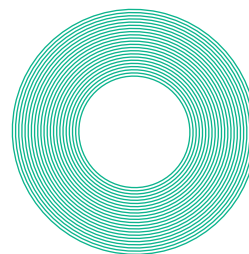
---

## OUR PRIORITY: TO TRAIN YOUNG TALENTS IN HEARING RESEARCH

In 2018, Fondation Pour l'Audition focused on training young talents to research to promote MD-PhD careers in Hearing Sciences. Two ENT residents were awarded master studentships:

- > **Mihaela Alexandru** for the project entitled **"Regeneration of the cochlear ribbon synapses with targeted therapy after noise trauma"** that she will lead at the Eaton-Peabody Laboratory of the Massachusetts Eye and Ear Infirmary in Boston, United States under the supervision of Professor Albert Edge
- > **Charlotte Benoit** for the project entitled **"Evaluation of the effectiveness of Letemovir and Maribavir antiviral treatment on hearing preservation in congenital MCMV infection in mice"** that she will develop at the Inserm U1141 laboratory at the Robert Debré hospital in Paris under the supervision of Professor Natacha Teissier.

In addition, Amandine Jarysta, PhD, obtained a postdoctoral fellowship to improve her research skills at the Jackson Laboratory in Bar Harbor in the United States. Her project, entitled **«Role of Daple and Girdin as regulators of Gai signaling in stereocilia development and hearing"** is being carried out under the supervision of Professor Basile Tarchini. The aim is to understand the role of the new Daple and Girdin proteins in the genesis of hair cells in the inner ear.





## 2018 SCIENTIFIC PRIZES

Every year, Fondation Pour l'Audition honors pioneering clinical or basic researchers in Hearing who have made major discoveries offering new hopes to people with hearing loss. In 2018, the foundation opened up its Scientific Grand Prize to international candidates for the first time.

During the awards ceremony in November, the following laureates were announced:

- > **Professor Ana Belén Elgoyhen**, director of the Institute for Research on Genetic Engineering and Molecular Biology (INGEBI-CONICET) in Buenos Aires, Argentina, for the discovery of the molecular basis and mechanisms for hearing control and protection in the inner ear
- > **Dr. Yann Nguyen**, ENT surgeon in the ENT department of the Pitié-Salpêtrière university hospital in Paris and the Inserm 1159 laboratory named "Robotic, mini-invasive surgical rehabilitation of hearing" for his contribution to the development of the first robot for cochlear implant surgery
- > **Dr. Jean-Julien Aucouturier**, scientist at the IRCAM laboratory in Paris, for his original, innovative research aimed at deciphering emotions in speech and music.



## NUMEROUS OUTREACH ACTIONS ON USHER SYNDROME

Fondation Pour l'Audition is a partner of the LIGHT4DEAF project on Usher syndrome<sup>1</sup> supported by the Investissements d'Avenir program, and coordinates the project's communication towards patients, their families, healthcare professionals and the general public.

Abundant information and news is posted regularly on the Usher info website ([www.usherinfo.fr](http://www.usherinfo.fr)) and social networks. In all, more than 600 publications have been posted and shared widely since the start of the project.

Since 2015, 10 events have been organized for the Usher community, bringing together 450 people. In 2018, patients, their families, professionals and the general public were able to attend:

- > The 4<sup>th</sup> counselling group (March 2018) on rehabilitation
- > The 2<sup>nd</sup> Usher Info symposium (March 2018) on research updates & community life
- > The 3<sup>rd</sup> public conference (June 2018) on cell therapy for Usher syndrome
- > The 5<sup>th</sup> counselling group (October 2018) on Usher syndrome in the family

These communications efforts will be pursued in 2019.

1. A rare genetic disease combining hearing loss, visual impairment sometimes and balance disorders





# FOR TODAY

---

## EDP-IDP SCHOOL FOR PARENTS OF CHILDREN WITH HEARING LOSS

**Fondation Pour l'Audition has teamed up with École des Parents et des Éducateurs d'Ile-de-France (EDP-IDP) to offer a support program for parents whose child has just been diagnosed with hearing loss.** After the birth of a child with hearing loss, families receive a wealth of information and important medical care. However, parent associations working in this area note the need for further information and non-medical support, particularly regarding the appropriate language and communication to use with their children. To meet this need, Fondation Pour l'Audition set up a dedicated "school for parents" in September 2018, providing information and support aimed at completing the development of family life for children with hearing loss and their entourage.

Through the school, **workshops** led by professionals offer specific parenting tips for families with hearing-impaired children. When necessary, the program will be accessible in French sign language and cued speech. By developing communications, like choosing the right language and understanding the principles and objectives of sign language or cued speech, creates the right conditions for education. We help parents to set up quality language with their children, and enable them to resume their parenting role. **Support groups** have also been designed for parents to share their experiences, express their feelings, discuss their difficulties and ask questions on hearing loss or other specific topics.

**10 WORKSHOPS/COUNSELLING  
GROUPS ORGANIZED AND  
23 PARENTS SUPPORTED IN 2018**





## CULTURE FOR ALL: SUPPORT FOR SCHOOL THEATER ACTIVITIES

Fondation Pour l'Audition's ambition is to give children with hearing loss a taste of theater and, through practice, help them to express themselves in words and movement, overcoming their shyness. Involved in the City of Paris "Art Pour Grandir" program, the theater workshop project takes an artistic, liberating approach.

In partnership with Théâtre de la Ville, the foundation has planned two complementary initiatives with teachers:

- > **Arts education for students:** each class will see three different shows over the year in sign language and cued speech, staged alternately at Théâtre de la Ville and the schools. Workshops will be offered prior to the shows to prepare the students, provide explanations and raise awareness of dramatic arts.
- > **Acting:** Théâtre de la Ville artists will train teachers from the two schools to produce a play and give acting classes to the students. These professionals will coach and train teachers throughout the year so they can carry over this initiative and put on their own show with the students at the end of the year.

This program was launched in September 2018 with Louise Michel school in La Courneuve, which accepts students with hearing loss. On November 22, 2018, three classes watched the first "We Are Monchichi" show by Wang Ramirez at Espace Pierre Cardin. French sign language was provided by Accès Culture and cued speech by Isos Accessibilité. Magnetic loops were also set up by Sonophore to enable every spectator to participate fully in the show. Two other shows are currently in preparation and will take place in April and June 2019.

## AWARENESS CAMPAIGNS FOR BUSINESSES AND HEARING TOUR

The foundation is convinced companies have an important role to play in raising employees' awareness of hearing health. This is why we offer half-day or full-day events in partnership with human resources departments and occupational health services. These events enable employees to take a hearing screening test in noise. Using tablets, the "digit-triplet test" assesses speech recognition in a variable noisy environment. During these events, the foundation mobilizes its teams, a healthcare professional (ENT resident, occupational doctor, etc.) and a representative of a charity for people with hearing loss. They inform, reassure employees, and distribute material and earplugs.

## MORE THAN 400 PEOPLE BENEFITTED FROM A HEARING SCREENING TEST IN 2018

In 2018, 270 people (70% women and 30% men) took the digit-triplet test. The average age was 41 at the companies in the Western suburbs of Paris where these information and awareness days took place (L'Oréal, Bolloré and Danone). According to the results, hearing performance in a noisy environment was good for 67% of participants, average for 23% and poor for 10%. The link between occupational health services and employees is essential in order to define the action to take for employees.

The foundation also organizes "Hearing Tour" events in a similar format (colloquiums, trade shows, university events, etc.). In this way, a further 140 people took the test in 2018.



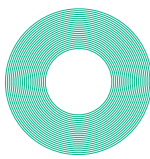
**EXHIBIT**  
**«TES YEUX SUR MES OREILLES»**  
**STEPHANE LAVOUÉ**

“ **INABILITY TO SEE SEPARATES THE HUMAN FROM THE WORLD OF THINGS. INABILITY TO HEAR SEPARATES THE HUMAN FROM THE WORLD OF HUMANS.** ”

**E. KANT**

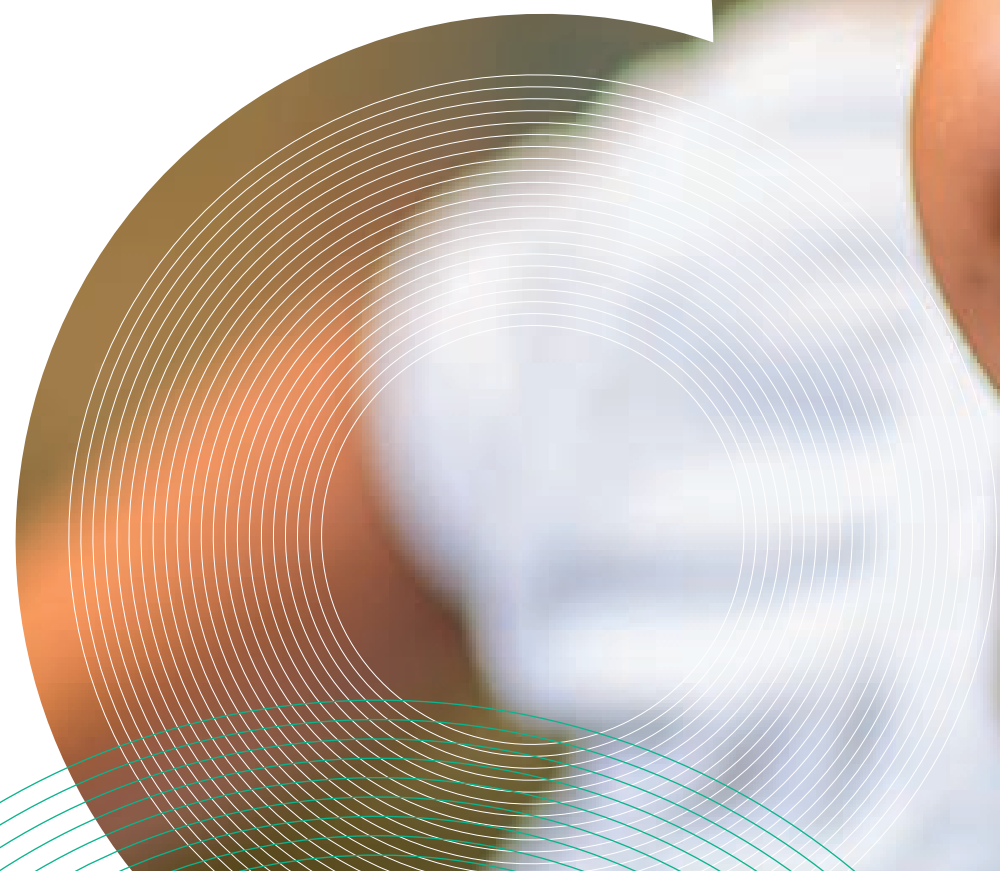
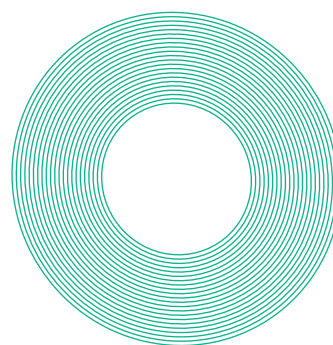
## **10 PROJECTS IN LINE WITH THE FOUNDATION'S VALUES AND AMBITIONS, WERE SUPPORTED IN 2018 IN RESPONSE TO OPEN REQUESTS:**

- > **CRESAM:** support to organize the training and awareness days on CHARGE syndrome (September 20-22, 2018).
- > **Envole-moi:** support for Manon Altazin's team to participate in the "Rêves de gosses" campaign, which enables disabled and abled-bodied children to fly for the first time in a tour of France by plane.
- > **ISOS Accessibilité:** training for cued speech coders in two specific areas through two modules: 1) "Accessibility by cued speed" for everyday adult situations (professional, social and cultural) and 2) "Coder-operators in a telecommunications relay service": coding at the pace of speech, remaining neutral and ensuring confidentiality. This training offers new career development opportunities to operators, building on their initial training.
- > **Bucodes:** support for the "6 millions de Malentendants" journal development and review of its distribution strategy
- > **UNISDA (national union for the social integration of people with hearing loss):** support for the union's development efforts to bring together audiences, expand the network of members and partners for greater impetus and offer services to improve the everyday lives of people with hearing loss.
- > **Les Chiens du silence:** enabling the acquisition, training and gifting of Thelma, a hearing assistance dog, to improve the life and increase the autonomy of a deaf person.
- > **Collectif Embuscade:** provision of foam earplugs and information on tinnitus for distribution at evening events organized by the collective.
- > **Association pour des Lieux de Parole Parents Enfants — ALPPE:** support to organize a colloquium for early childhood experts on the theme "Unease in the family".
- > **Association de Neurofibromatoses et Recklinghausen:** Support for the organization of World Neurofibromatosis Days.
- > **Centre d'Information sur le Bruit — CidB:** support for the organization of two events:
  - The second national "Noise & Health" days (November 28, 2018): a conference workshop entitled "How to make the professional world more intelligible to people with hearing loss?" chaired by Fondation Pour l'Audition
  - A national colloquium entitled "Amplified sound: new regulation takes the stage!" (December 5, 2018)



# 2019 OUTLOOK

- > **Launch of a call for translational research projects** (acceleration of the development of new therapies) with the UK-based charity Action on Hearing Loss
- > **Launch of PhD studentships** for qualified speech therapists and audiologists
- > **Launch of travel awards** for ENT residents in partnership with the Association for Research in Otolaryngology in the United States
- > **Awareness film** on Usher syndrome
- > **Launch of an university accessibility plan** with a pilot project at Paris Nanterre University
- > **Launch of the "Speech Therapy and Deafness"** platform ([orthophonie-et-surdite.fr](http://orthophonie-et-surdite.fr)) to help 18,000 French speech therapists better understand and treat hearing loss in children and adults
- > **Launch of a partnership with ENSCI school** to design quiet relaxation pods at music festivals
- > Development and launch of **a hearing screening app**
- > Opening of the **Institut de l'Audition**





atom

# A FEW FIGURES in K€

## OVERALL 2018 BUDGET

### EXPENDITURES

**7 538**

Research support program	1 710
Institut de l'Audition	3 071
CERCA	302
For Today support program	586
Communication and resource development	677
General operations	1 192

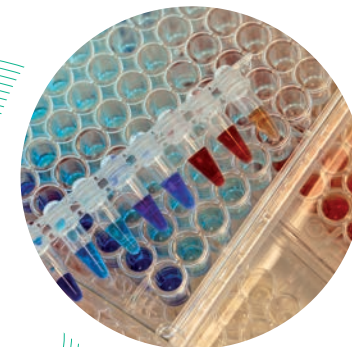
### RESSOURCES

**7 538**

FBS support	6 745
Recovery of FBS dedicated funds	652
LIGHT4DEAF Project	71
Donations	39
Reserves	31

## TEAM

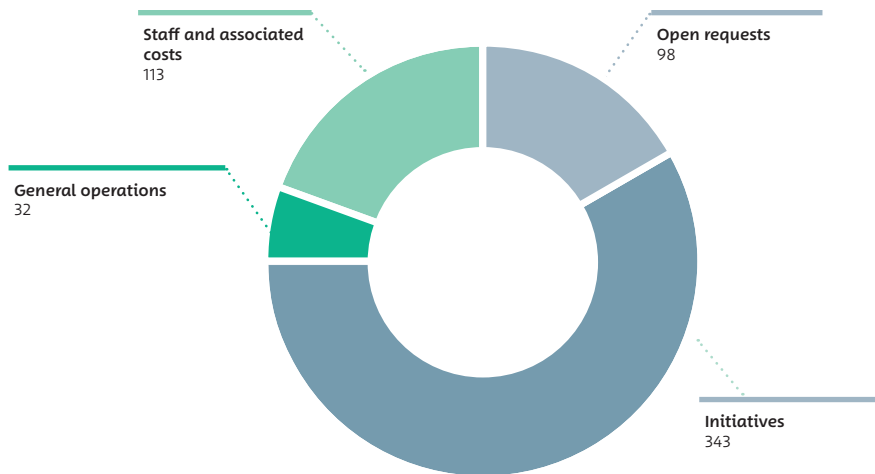
Staff early 2018	9
Staff end of 2018	10



# 2018 ACTIVITY BY DEPARTMENT

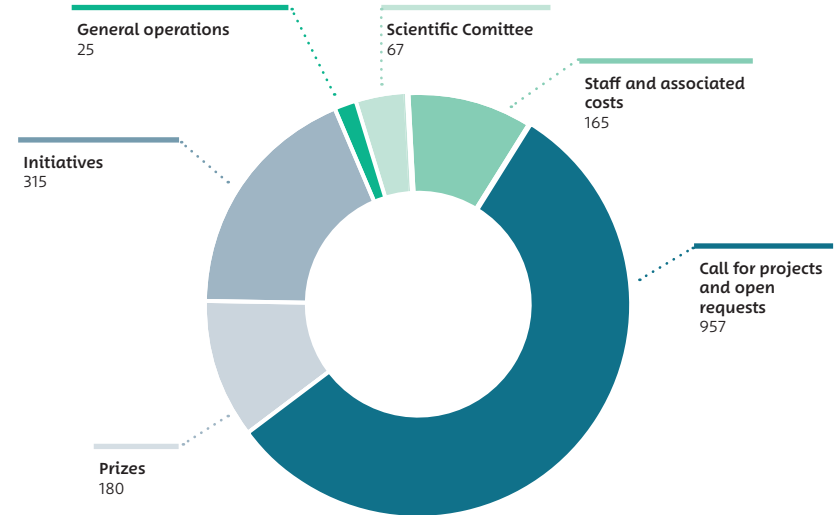
## FOR TODAY SUPPORT PROGRAM 586

Sponsorship and initiatives	441
Associated costs	145

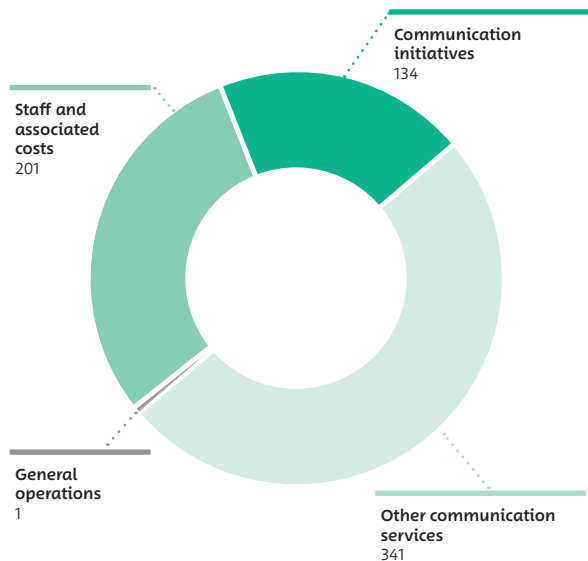


## RESEARCH SUPPORT PROGRAM 1 710

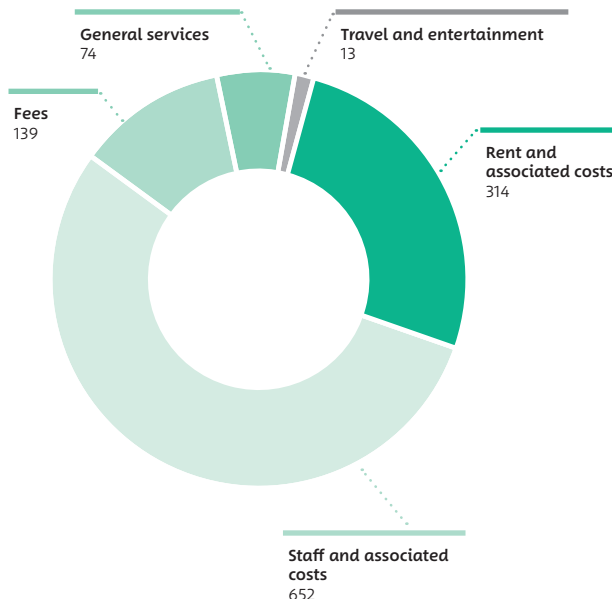
Sponsorship and initiatives	1 452
Associated costs	257



## COMMUNICATION AND RESSOURCE DEVELOPMENT 677



## GENERAL OPERATIONS 1 192



## INSTITUT DE L'AUDITION AND CERCA 3 373

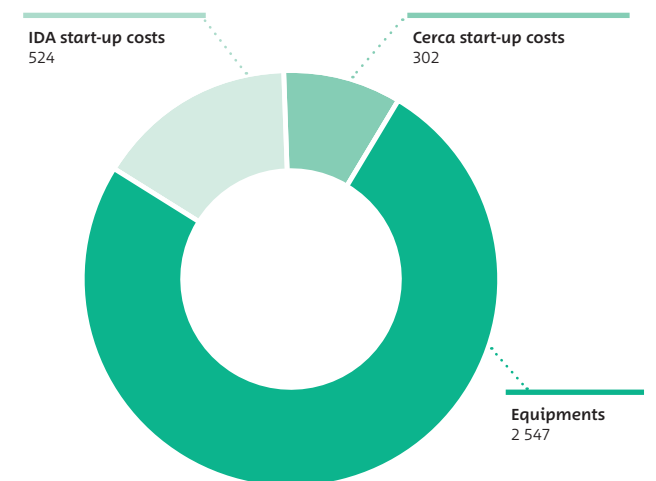




Photo credits : UMR1109 INSERM Strasbourg / INSERM- Patrick Latron / Laurent Attias

## SUPPORT US

We need you. To make a donation, visit our website:

**[www.fondationpourlaudition.org](http://www.fondationpourlaudition.org)**



Fondation Pour l' Audition [contact@pourlaudition.org](mailto:contact@pourlaudition.org)

[www.fondationpourlaudition.org](http://www.fondationpourlaudition.org)