OUR 2019 ACTIVITIES

Recognized as a public-interest organization since 2015
“The ear is the avenue to the heart,” said Voltaire.

To improve hearing health, numerous roads were travelled by Fondation Pour l’Audition in 2019.

The road to prevention and awareness was taken, since 2019 was the year we started developing the Höra hearing screening app. As the first app to offer a scientifically approved test, Höra enables users to effectively evaluate their hearing health.

In November, we launched a campaign aimed at companies to raise awareness of inclusion in the workplace for people with hearing loss. We also addressed hearing loss in recreational environments, taking our first steps in the music festival industry with the listening breaks areas project to promote listening breaks.

The road to scientific progress saw the launch of the first call for translational research in cooperation with the British charity Action on Hearing Loss, aimed at developing new drug, gene or cell-based approaches for the treatment of hearing disorders, and tinnitus.

In 2019, the Foundation also organized its second “Listening to Life” evening event, where two scientific prizes were awarded to eminent basic and clinical researchers.

The road towards the future was taken, thanks to the creation of Alliance Pour l’Audition (i.e. the Hearing Alliance) with Institut Pasteur and Greater Paris University Hospitals (AP-HP) to advance hearing health. Founded on Fondation Pour l’Audition’s initiative, Alliance Pour l’Audition aims to improve hearing health through work in every area: basic, translational and clinical research, along with progress in society. The alliance includes high-profile projects, including the Institut de l’Audition and the CeRCA network of clinical research centers in audiology.

All the projects that you will discover over these pages have been made possible thanks to the superb team of the Foundation, but also thanks to the unfailing support and mobilization of our Board of Directors*, who I wish to thank warmly.

Together, let’s keep listening to life!

* Françoise Bettencourt Meyers, Honorary president; Jean-Pierre Meyers, President; Olivier Brault, Vice-President; Nicolas Brusson, Treasurer; Armand de Boissière; Étienne Caniard; P’ Lionel Collet; Jean-Marie Dru; P’ Bruno Frachet; Cédric Lorant; Anne Paoletti, Commissioner; Olivier Tcherniak; P’ Antoine Triller
Supporting research is essential to Fondation Pour l’Audition’s work. In 2019, this mission took on a new dimension with Alliance Pour l’Audition, a new alliance with Institut Pasteur and Greater Paris University Hospitals.
ALLIANCE POUR L’AUDITION

Founded on Fondation Pour l’Audition’s initiative, Alliance Pour l’Audition is a leading group of experts aiming to improve hearing health through work in every area: basic, translational and clinical research, as well as progress in society.

The alliance includes high-profile projects, including the Hearing Institute and the CeRCA network of clinical research centers in audiology. Alliance Pour l’Audition aims to mobilize every talented expert sharing the ambition of improving the lives of people with hearing loss. How? By building bridges between researchers and physicians to accelerate audiology research and treat all types of hearing loss.

THE MANIFESTO

We are
Researchers,
Scientists,
Geneticists,
Physicists,
Physicians,
Hearing care professionals,
Speech therapists,

Biologists,
Chemists,
Psychologists,
Academics,
Engineers,
Manufacturers,
Patient advocacy groups, and
People with hearing loss.

Together, we form an interdisciplinary national and international network in the hearing field.

Together,
we commit to accelerating research and its applications.

Together,
we aim to understand and treat all types of hearing loss.

Together,
we carry this hope and act without delay to improve life for people with hearing loss.
NATIONAL RESEARCH SUPPORT PROGRAM: NEW PROJECTS

Our national research support program assists hearing stakeholders, whether speech therapists, hearing care professionals, doctors or researchers, throughout their training and careers. Each application is carefully assessed by the Foundation’s Scientific Committee, which is chaired by Professor Karen B. Avraham, Vice Dean at the Sackler Faculty of Medicine, Tel Aviv University, Israel. This year, to promote translational research and enable young talent to receive research training, our program has been enhanced by:

- The launch of a call for translational research with Action on Hearing Loss, a world-class British charity
- The opening of PhD studentships for qualified speech therapists and hearing care professionals
- The launch of travel awards for ENT residents, in partnership with the Association for Research in Otolaryngology (ARO) in the United States.

SINCE 2013
€6,5 M
54 LAUREATES
Fifteen laureates have already been announced in the following categories:
- open requests (2),
- scientific prizes (2),
- postdoctoral fellowships (1),
- ARO-FPA travel awards (2),
- master studentships (1),
- PhD studentships (2),
- laboratory grants (4)
- and translational research grants (1).

In total, €1.4 million has been allocated this year to applied:
- research projects (3),
- medical and audiology research (5),
- basic research (6)
- and psychological and social research (1).

The full details on our 2019 laureates are available on fondationpourlaudition.org

18 laboratory grants
11 scientific prizes
11 open requests
7 postdoctoral fellowships
3 master studentships
2 PhD studentships
2 ARO-FPA travel awards
Since 2016, the Fondation Pour l’Audition’s Scientific Prizes have celebrated and supported talented researchers in the hearing field in France and worldwide for their scientific progress and breakthroughs.

Professor Jeffrey R. Holt (Boston Children’s Hospital/Harvard, USA) received the 2019 Scientific Grand Prize for his discovery of the role of a key protein in the auditory system. This protein, called “TMC1,” provides the basis for hearing, enabling the sound waves perceived by the ear to be converted into electrical signals that can then be decoded and processed by the brain. Highly involved in translational research, Professor Holt is striving to develop gene therapy with the aim of restoring auditory and vestibular function in people with hearing loss.
USHER SYNDROME: A FILM TO RAISE AWARENESS IN 2019

Fondation Pour l’Audition is a partner of the LIGHT4DEAF university hospital project on Usher Syndrome\(^1\) supported by the Investissements d’Avenir program since 2015, and coordinates communication aimed at patients, their entourage, healthcare professionals and the general public.

Available in French sign language and with subtitles, a film on Usher syndrome was developed to raise public awareness of the everyday experience of people with hearing, visual and balance impairment. The film also presents the lines of research currently being explored for this condition.

https://www.youtube.com/watch?v=57oHgp3zo2o

A number of events were organized throughout the year for patients, their entourage, healthcare professionals and the general public:

- The 3\(^{rd}\) Usher Info symposium, on Usher syndrome research and community life
- The 6\(^{th}\) information and exchange meeting, on parasports
- The 4\(^{th}\) public conference, on Usher syndrome and sensory therapy
- The 7\(^{th}\) information and exchange meeting, on Usher syndrome and sensory therapy

In addition, information and news updates were posted regularly on the Usher Info website for the general public (www.usherinfo.fr) and professionals (pro.usherinfo.fr) as well as on social networks.

1. A rare genetic disorder involving hearing and visual loss, sometimes combined with balance impairment
At the foundation, we have noticed that many healthcare professionals and medical social workers would like to be supported in their everyday care management of hearing loss, a topic that is sometimes poorly covered in their training. That is why we decided to support two professions that are strategic in our field: otorhinolaryngology and speech therapy.
On March 22, 2019, Fondation Pour l’Audition and the French National Federation of Speech Therapists (FNO) created the first free, easy-access web platform to help speech therapists working with people with hearing loss. The “Orthophonie & Surdité” platform aims to provide answers on treatment for hearing loss, which is highly specific, depending on numerous aspects: the type of hearing loss, the patient’s age, the psychological impact of discovering hearing loss, the language used, and so on.

This platform is available to speech therapists who want to join forces, find information, self-train and get involved in hearing health. In 2019, more than 900 speech therapists signed up to the platform.

Speech therapists emphasize the importance of being able to discuss clinical cases with each other, as well as other medical experts (multidisciplinary staff). They have a genuine desire to join a network for exchanging best practices. On December 12, 2019, in Dax, FPA and FNO organized a first meeting for speech therapists, ENT doctors, ergonomists and other specialists. In 2020, FPA and FNO will aim to organize this type of event and build momentum on the topic in several departments of France.
HELPING TO IMPROVE ENT KNOWLEDGE

Fondation Pour l’Audition wanted to support certain action by the French ENT Society (SFORL) in cooperation with the International Federation of ORL Societies (IFOS) to improve ENT training and knowledge. Two international hearing courses for qualified young otorhinolaryngology doctors were organized in 2019. The first took place in Dubai (United Arab Emirates) on March 28-30, 2019, with 50 participants and 28 speakers. The second took place on November 24-26 in Ho Chi Minh City (Vietnam) with 300 participants and 35 local and international speakers.

In addition, the Foundation supported the creation and launch of a website with an “Educational Material” search engine enabling qualified otorhinolaryngology doctors worldwide to access a high-quality scientific database (available on www.ifosworld.org). At the end of 2019, more than 300 articles were available on audiology, otology and balance disorders.
Hearing loss can involve everyday difficulties that sometimes seem impossible to overcome for the people facing them. At the Foundation, we want to offer everyone with hearing loss who wants or needs help the means to improve their lives.
TRAINING FOR PARENTS OF CHILDREN WITH HEARING LOSS

The partnership set up between Fondation Pour l’Audition and École des Parents et des Éducateurs d’Île-de-France (EPE-IDP) bore fruit in 2019. Since the launch of the program, a total of 19 sessions have been held and 43 parents have participated in the different workshops. A new program is underway for the 2019-2020 academic year.

As a hub of information and support, this school provides specific parenting advice to families of children with hearing loss. Led by professionals, the different workshops and discussion groups have enabled parents to better understand their children’s hearing loss and the different communication means and languages that can be adopted with them. After participating, parents reported a high level of satisfaction with the program and its organization.

Building on this success in the Paris region, Fondation Pour l’Audition, in partnership with the National EPE Federation, launched a regional diagnostic to disseminate and adapt this program effectively in other departments of France.
CULTURE FOR ALL:
SUPPORT FOR SCHOOL DRAMATIC ARTS

Launched at the start of the 2018-2019 academic year for a three-year period, the first year of the project for school dramatic arts was completed in June 2019. In partnership with Théâtre de la Ville de Paris, this program was renewed for the 2019-2020 academic year in two schools teaching children with hearing loss.

In 2019, Louise Michel school in La Courneuve opened its doors to theater, with two elementary and junior classes attending three plays: We are Monchichi, Le Bain and J’ai trop peur accessible in French sign language and cued speech, and with hearing loops available. Each of these plays was preceded by a preparation workshop led by actors from the shows. After attending the plays and supplementary classes given by Théâtre de la Ville, the pupils and teachers put on several plays at the end of the school year.

Numerous pupils have benefitted from this project since September 2019. Buffon elementary school in Paris has signed up, with two elementary and junior classes of pupils with all levels of hearing loss. The youngest have already watched the Ipet show. Some 62 children will benefit from this cultural program, like their peers from Louise Michel school, which is continuing to host the project. A total of 130 children will benefit from the program in 2019-2020.

The Foundation also supports training on hearing loss and accommodating audience members with hearing loss for Théâtre de la Ville personnel. In 2019, 12 employees benefitted from training provided by Bucodes.
FIL SANTÉ JEUNES

As Fondation Pour l’Audition celebrated the first year of a telecommunications relay service for people with hearing loss, this anniversary also provided an opportunity to announce that Fil Santé Jeunes would be accessible to young people with hearing loss, enabling them to communicate in French sign language, cued speech or simultaneous transcription. Fil Santé Jeunes is a telephone service that addresses health issues and disease prevention measures introduced by the authorities for young people. It is a free, anonymous hotline open 7/365, along with a website (www.filsantejeunes.com) and communication by chat and email. EPE-IDF is managing this service with Unanimes (the French union of national associations for the inclusiveness of people with hearing loss) to train the professionals listening to the specific problems encountered by young people with hearing loss, and enable them to communicate in the preferred communications method of those in distress through a telecommunications relay service. In this way, Fil Santé Jeunes will be able to:

- Better inform young people on their health
- Prevent psychological distress by identifying attitudes that could lead to risky situations, guiding young people to dedicated services and improving the well-being of young people with hearing loss
- Offer an emergency procedure to suicidal young people with hearing loss.

Prévention Santé 3.0
Sexualité Contraception Amour Mal-être...

0 800 235 236
filsantejeunes.com

Fil santé jeunes - anonyme et gratuit pour les 12-25 ans
tous les jours de 9h à 23h

LE LIEN QUI TE LIBERE
CHARITY HACKATHON

On the initiative of technology marketing agency LineUp7, Fondation Pour l’Audition helped organize a charity hackathon aimed at developing a learning tool for French cued speech and communications with children with hearing loss. This project was carried out with ALPC, the national association for French cued speech, which aims to promote the potential of this form of communication.

Several 48 hour-brainstorming topics were proposed to a wide range of talent, including data scientists, data analysts, IT developers, UX designers and creatives:

- Optimizing and adapting cued speech learning software aimed at children for tablets/smartphones
- Creating a “transcoder” app for children to help them learn cued speech
- Creating a “coding head” capable of instant coding through voice recognition.

Attended by approximately 50 people, including the organizers and selection panel, this event led to five innovative open source projects facilitating cued speech learning and the autonomy of children and parents.
It can never be said too often that our hearing is precious since it is unique and cannot be replaced once lost. It is therefore essential for the foundation to raise awareness of the importance of taking care of hearing among as many people as possible of every age.
HÖRA

Many mobile apps offer hearing screening in noisy environments but none have achieved consensus in the scientific community.

In 2019, Fondation Pour l’Audition developed the first scientifically approved hearing screening app for smartphones and tablets, known as Höra.

Intuitive and easy to use, Höra assesses the user’s hearing against a noisy background, producing clear results in just a few minutes.

With Höra, users can monitor their hearing throughout their lives, learn more through numerous tips, share the results with their entourage and schedule reminders for their next tests. This free app is available on the App Store and Google Play Store.
AWARENESS CAMPAIGN ON WORKPLACE INCLUSIVENESS FOR PEOPLE WITH HEARING LOSS

During European Disability Employment Week, Fondation Pour l’Audition wanted to remind people of the key role played by companies in inclusiveness. Companies must lead the way with inclusion, information and anticipation to optimize working conditions for employees with disabilities. That is why the foundation carried out a corporate awareness campaign with agency Tell Me The Truffe to promote inclusiveness for people with hearing loss in the workplace. Through five different situations, this campaign highlighted gaps in the perceived behavior of employees with hearing loss or with healthy hearing in everyday workplace situations and suggested tangible solutions for creating a more inclusive and comfortable work environment for all. Since then, Fondation Pour l’Audition has made this poster campaign available to companies and 18 have requested it.
Il est peut-être antipathique.

OU PEUT-ÊTRE PAS.

Plus d’une personne sur dix est concernée par une déficience auditive.

Pour la compenser, certaines peuvent avoir recours à une prothèse, d’autres à la lecture labiale, certaines maîtrisent la langue des signes française, d’autres pas…

Chaque situation est unique. Dans tous les cas, le premier réflexe à avoir, c’est de veiller à bien se placer en face de la personne pour lui parler. C’est simple non ?
AREAS FOR LISTENING BREAKS

Approximately 67% of young people under 20 have already experienced tinnitus. Behind this worrying figure lies a Fondation Pour l’Audition mission: to help protect young people’s hearing by ensuring safe access to entertainment and amplified music. To this end, following the French Ministry of Culture’s decree 2017-1244 (adopted on August 7, 2017), requiring music festivals to create areas for listening breaks, Fondation Pour l’Audition has teamed up with ENSCI-Les Ateliers to design listening break areas to make available to festival organizers.

From February to June 2019, 19 ENSCI students designed areas to encourage festival goers to take a break from noise and protect their hearing. Presented at Solidays and tested by attendees, the nine projects were then presented at the end of June to festival organizers. These projects ranged from a big wheel and a hammock to a “submarine” (the Escape Sound), unique encounters and mystic processions.
A first project, **The Totem** was produced at Rock en Seine festival in the summer of 2019, and was popular with both organizers and festival goers.
For its second year, the “Tes Yeux Sur Mes Oreilles” photo exhibition organized by association Droit Pluriel with the support of Fondation Pour l’Audition took place in December on the railings of Tour Saint-Jacques in Paris. The general public was able to share the everyday life of deaf people through poetry testimonials and discover their experience of hearing loss at work and play, in love and in the eyes of other people.

“I don’t want to hide my hearing aids under my hair anymore.”

“I’m tired of pretending I can hear.”

“I want to accept my hearing loss and not be ashamed of it.”
CORPORATE INFORMATION AND AWARENESS ACTION AND AUDITION TOUR

The Foundation wants to help companies to raise awareness of hearing health among their employees by offering half-day of full-day events in partnership with human resources and occupational health departments. We offer employees a hearing screening test in noisy environments. Administered through interactive tablets, this “digits-in-noise test” assesses speech comprehension in fluctuating noise. To do so, the foundation mobilizes its teams, a health professional (for example, an ENT resident or occupational doctor) and a representative from a charity for people with hearing loss. Together, they inform and advise employees, while distributing documentation and earplugs. In 2019, 935 people (53% men and 47% women) took the digits-in-noise test. The average age of people taking the test during these corporate information and awareness days was 38.5. 69% had good hearing in a noisy background, compared with 21% average and 10% poor. To follow up on these results and define the right action for employees, occupational health services are essential. In addition, the Foundation has carried out further action in the same format, called “Audition Tour” at colloquiums, trade events, universities, etc., enabling more than 430 people to take the test. Fondation Pour l’Audition will pursue and reinforce its action through the Höra hearing app, available in early 2020.
Fondation Pour l’Audition received 61 open requests and supported 19 projects in line with its values and ambitions.

These projects involve three main goals:

**SUPPORTING AND TRAINING PROFESSIONALS**

- Creating “Agi-Son Connect,” a platform for music industry professionals on auditory risks
- Organizing a national meeting day for French cued speech professionals through ANCO, the national association of cued speech coders
- Developing videos to better accommodate patients with hearing loss, with SENSGENE

**INFORMING THE GENERAL PUBLIC AND RAISING AWARENESS**

- Designing “Les Fées Spéciales,” an inclusive animated film for children, promoting a universal sign language
- Enabling young people from IRSA to produce videos to talk about their hearing loss to their classmates and teachers
- Helping CiDB (a noise information center) to launch a school prevention campaign on the auditory risks involved in different professions
- Participating in the “Philoscène” festival for all ages, highlighting hearing loss and making all its workshops accessible
IMPROVING EVERYDAY LIFE FOR PEOPLE WITH HEARING LOSS

- Introducing Panthéea smart caption glasses at Edouard VII theatre, tested by ARDDS 75 (an association protecting the rights of people who have lost their hearing) to encourage people to return to the theatre.
- Funding health campaigning and support for healthcare professionals in retirement homes by ADSM Surdi 50 (an association for people with hearing loss in La Manche) to facilitate communication with residents.
- Organizing Bucodes congresses to raise awareness and demonstrate ways of improving everyday life for people with hearing loss.
- Supporting lip reading and sophrology workshops by SURDI 49 for people with hearing loss or tinnitus.
- Helping people with hearing loss to play music through dedicated workshops set up by Cité de la Musique – Philharmonie de Paris.

And making congresses, themed days and other events accessible.
2020 OUTLOOK

- Reinforced action to provide information and hearing screening in companies

- Launch of a student mentoring program focusing on “access to higher education for young people with hearing loss and workplace integration”

- Reinforced organization of multidisciplinary staff in cooperation with FNO for hearing care

- Launch of a project for a better accessibility to rights for people with hearing loss

- Creation of a focus group of general practitioners with Collège de Médecine Générale on the use of the Höra hearing app

- Launch of an observational study on hearing health in the workplace with Société de Médecine du Travail de l’Ouest Ile-de-France

RESEARCH

- Launch and inauguration of the CeRCA network

- 2020 International Usher Info symposium

- Launch of the AUDINNOVE university hospital research project to develop a gene therapy trial in children with otoferlin deficiency

- Support for the Lancet Commission on Hearing Loss aimed at improving hearing care worldwide
# A FEW NUMBERS

## OVERALL BUDGET

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