



THE AUSTRALIAN TEMPORAL BONE BANK

DONOR INFORMATION FORM

Please return the completed forms to:

Australian Temporal Bone Bank
Department of Otolaryngology
University of Melbourne
Level 2, Royal Victorian Eye and Ear Hospital
32 Gisborne Street
East Melbourne 3002
Victoria

Your donation toward the future of hearing & balance research

Confidential medical information for research purposes

Instructions for Completing the Australian Temporal Bone Bank Donor Program Confidential Medical Information Form

Thank you for completing this medical information form. The more information you can provide, the more valuable your anatomical gift will be. If necessary, use additional pages to explain your ear disorders. If you have any questions, please contact Catherine Ngondi on Ph: 9929 8281 or email: cngondi@unimelb.edu.au

- 1 This form should be completed by the person wishing to make an anatomical gift of his/her temporal bones.
- 2 Many of the questions have a box () next to them. Tick the box if the answer is "yes". Leave the box blank if the answer is "no". Insert a question mark (?) if you do not know or are unsure of the answer.
- 3 Each form should contain information on one person only. Should other family members or friends wish to become temporal bone donors, please either photocopy this form, print out another copy, or request additional copies from the Registry.
- 4 This confidential medical information form provides the Registry with some of your medical history pertinent which is important for us to be able to understand your hearing/balance to your ear disorder. This form along with a signed consent form completes the bequest of your temporal bones.
- 5 The scientific value of your temporal bones is greatly enhanced if accompanied by up-to date medical records. Donors will be contacted every 3-5 years to update their records.

The Australian Temporal Bone Bank Medical Information Form

(Please type or print legibly)

The “donor” is the individual who is ‘leaving’ their temporal bone to the Australian Temporal Bone Bank.

DONOR:

Name:

Date of Birth:

Home Address:

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City, State, Postcode:

Home Telephone:MOBILE:.....

Business Address:

City, State, Postcode:

NEXT OF KIN:

Name:

Address:.....

.....

City, State, Postcode:

Home Telephone: MOBILE:

Relationship to Donor:

1. What is the exact diagnosis (or diagnoses) of your hearing or balance disorder(s)?

Diagnoses:

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2. Describe your hearing/balance disorder(s) in your own words, giving onset, duration, treatment and cause. (E.g. "I started losing hearing in both ears at age 25. Hearing tests were done and I was diagnosed as having otosclerosis. I underwent a successful stapedectomy in my right ear at age 35").

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- Ear surgery (if yes, please list operations below)
- Drug treatment that resulted in hearing or balance loss (e.g., chemotherapy (cancer treatment), lasix ('fluid' medication), gentamicin (or any other antibiotic given through a 'drip'), problems with walking, feeling things with your hands or feet (including the floor when walking), with your speech or with co-ordination (that is, fine movement such as doing up buttons on clothing))
- Neurological or brain and nerve illness (e.g., seizures, stroke, tumor, infection, etc.)
- Difficulty with walking, feeling things with your hands or feet (including feeling the floor when walking), with your speech or with co-ordination (that is, fine movement such as doing up buttons on clothing)
- Brain or spine surgery
- Ear infections (bacterial or viral)
- Injury to ear (skull fracture, etc.)
- Meningitis
- Radiation therapy to head, face or neck
- I wear a hearing aid

3. Do you currently have, or have you ever had, any of the following symptoms? Please tick the boxes that apply, and indicate right or left ear, if appropriate. If you are not sure, please place a question mark (?) in the appropriate box. Use the space under question 5 to give details of each item marked

	Right Ear	Left Ear
<input type="checkbox"/> Hearing loss
<input type="checkbox"/> Ear drainage (pus)
<input type="checkbox"/> Tinnitus (noises or ringing in the ear)
<input type="checkbox"/> Ear pain
<input type="checkbox"/> Ear pressure or fullness
<input type="checkbox"/> Facial nerve paralysis
<input type="checkbox"/> Dizziness or vertigo

4. Have you ever had any of the following? If so, check the appropriate box, and use the space below to give details of the item checked.

- Exposure to loud noises (e.g., gunfire, military service, jackhammer at work, etc.)
- Ear surgery (if yes, please list operations below)
- Drug treatment that resulted in hearing or balance loss (e.g., chemotherapy (cancer treatment), lasix ('fluid' medication), gentamicin (or any other antibiotic given through a 'drip'), problems with walking, feeling things with your hands or feet (including the floor when walking), with your speech or with co-ordination (that is, fine movement such as doing up buttons on clothing))
- Neurological or brain and nerve illness (e.g., seizures, stroke, tumor, infection, etc.)
- Difficulty with walking, feeling things with your hands or feet (including feeling the floor when walking), with your speech or with co-ordination (that is, fine movement such as doing up buttons on clothing)
- Brain or spine surgery
- Ear infections (bacterial or viral)
- Injury to ear (skull fracture, etc.)
- Meningitis
- Radiation therapy to head, face or neck
- I wear a hearing aid

5. Please provide explanations or details on any of the boxes you marked in questions 3 or 4.

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6. List all non-ear problems or illnesses that you have (e.g., diabetes, high blood pressure, rheumatoid arthritis, etc.) and non-ear surgery that you have had. **Include a list of medications you have taken to treat these problems.

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7. Is there a **family history** (parents and their brothers and sisters, grandparents, your brothers and sisters, etc. **not** your relatives by marriage) of any of the following? Tick all appropriate boxes.

- Hearing loss in old age
- Otosclerosis
- Balance (equilibrium) disorders
- Difficulty with walking, feeling things with your hands or feet (including the floor when walking), with your speech or with co-ordination (that is, fine movement such as doing up buttons on clothing)
- Hearing problems in childhood or as an adult
- Deformity of the ear at birth
- My parents or grandparents are/were related by blood (brother and sister, first or second cousins, etc.)
- A certain kind of hearing loss runs in my family

8. Please provide explanations or details below on any of the boxes ticked in question 7.

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AUSTRALIAN TEMPORAL BONE BANK DONOR CONSENT FORM

I, hereby donate:

My temporal bones

My brain structures associated with hearing and balance

This gift is made to the Royal Victorian Eye and Ear Hospital and The University of Melbourne for the purposes of medical research and/or education. I understand that these tissues will be removed by a medical doctor, coroner or other qualified person **without cost** to my estate, my family or my friends.

I also authorize the release of all of my medical records including results of post-mortem examination to the Program. This authorization includes any examinations, tests and review of medical history necessary to assure medical acceptability of the donated tissues.

DONOR:

.....
(Donor's signature)

.....
(Date of Birth)

.....
(Name – Please Print)

.....
(Date signed)

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.....
(Otological Diagnosis)

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(Donor's Address)

.....
(City, State, Postcode)

.....
(Phone Number)

NEXT OF KIN (or Chosen Representative)

WITNESS

.....
(Signature of Next of Kin / chosen)

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(Signature of Witness)

.....
(Name – Please Print)

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(Name – Please Print)

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(Address)

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(Address)

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(City, State, Postcode)

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(City, State, Postcode)

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(Phone)

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(Phone)

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(Date signed)

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(Date signed)

Relationship to Donor:

A copy of this form will be sent to you for your will or funeral instructions.

Research co-operation

We ask that you consider allowing us to share the pathology results of your temporal bone and/or brain structures associated with hearing and balance shared with the largest bank of temporal bones in the U.S.A.; the NIDCD National Temporal Bone, Hearing & Balance Pathology Resource Registry Massachusetts Eye & Ear Infirmary. Any information that is shared is confidential and does not contain your name or any personally identifying details.

- Yes, I agree to have my medical details and the results of my temporal bone and/or brain structures associated with hearing and balance shared with the NIDCD National Temporal Bone, Hearing & Balance Pathology Resource Registry Massachusetts Eye & Ear Infirmary. → Please complete the question below.
- No, I am not interested in having my information shared with the NIDCD National Temporal Bone, Hearing & Balance Pathology Resource Registry. → Please proceed to the next page.

Race and/or Ethnic Origin (tick one)

Note: The category that most closely reflects the individual's recognition in the community should be used for purposes of reporting mixed racial and/or ethnic origins.

- American Indian or Alaskan Native.* A person having origins in any of the original peoples of North America, and who maintains a cultural identification through tribal affiliation or community recognition.
- Asian or Pacific Islander.* A person having origins in any of the original peoples of the Far East, Southeast Asia, the Indian subcontinent, or the Pacific Islands. This area includes, for example, China, India, Japan, Korea, the Philippine Islands and Samoa.
- Black, not of Hispanic origin.* A person having origins in any of the black racial groups of Africa.
- Hispanic.* A person of Mexican, Puerto Rican, Cuban, Central or South American, or other Spanish culture or origin, regardless of race.
- White, not of Hispanic origin.* A person having origins in any of the original peoples of Europe, North Africa, or the Middle East.
- Another group not listed.
- Check here if you do not wish to provide some of all of the above information.

RESEARCH PROJECT TO OBTAIN DNA FROM BUCCAL (CHEEK) SWABS OR BLOOD FROM TEMPORAL BONE DONORS

Histopathological studies of temporal bones and related brain structures donated after death by individuals with hearing or balance disorders can provide very valuable information about the causes and mechanisms of these disorders. The utility of such studies can be enhanced even further by combining the histopathological analysis with DNA studies of genes involved in hearing and balance. It has become apparent in the last several years that the functions of hearing and balance are controlled and determined by a large number of genes. Estimates range from 200 to more than 1,000 genes. It is difficult to extract DNA for genetic studies from temporal bones and related brain tissue; the DNA is often fragmented and contaminated during tissue processing.

Therefore, it would be very valuable to obtain the DNA from a clean and uncontaminated sample to enhance the value of the temporal bone studies. Individuals who are currently registered as temporal bone donors or those who are considering temporal bone donation are requested to also donate a sample of their DNA obtained from a small blood sample or by using sterile buccal (cheek) swabs. Cheek swabs will be sent by mail to donors. They are extremely easy to use- the sterile brush at the end of the swab is rubbed against the inside of the cheek back and forth several times just like a toothbrush. The brush is placed back in the sterile container and a prepaid envelope will be provided to send the brushes back to the Registry in the mail.

There are virtually no risks of using the cheek swabs. The procedure is as simple and painless as brushing one's teeth.

Each donor's DNA sample will be coded. Then the DNA sample will be stored in a freezer at -70°C under this code and no DNA or genetic research will be done until the donor's death. After death when the temporal bones are obtained, the frozen DNA samples will be used only for research purposes, and only to investigate genes involved in hearing and balance. Results of this research may be presented or published for use by the medical or scientific community, but confidentiality of donors will be protected at all times. No identifying information will be made available to other physicians, researchers, insurance companies, or any other individual or agency, unless specifically requested by the donor prior to death in the form of a written, signed and confirmed release.

Participation in this study is entirely voluntary. A donor may choose not to donate his/her DNA from the cheek swab and instead to only donate the temporal bones and/or related brain structures. A donor may also withdraw from the study in the future by informing the Registry in writing, in which case his/her DNA sample will be destroyed. There will no cost to any donor for participating in this study.

Yes, I am interested in participating in the Bank's research project to obtain DNA from buccal (cheek) swabs or a blood sample, from temporal bone donors.

No, I am not interested in participating in this project at this time.

Name:

Street Address:.....

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City, State,

Signature..... Date.....

Please return the completed forms to:

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