



## **Informed Consent to Participate in Research and Authorization to Collect, Use and Share Your Health Information**

**forMemory** is a group of individuals with dementia and their friends and families whose mission is to bring together people affected directly or indirectly by Early Onset Alzheimer's and Related Diseases, to increase their emotional, spiritual, and physical well-being. One of the goals of the group is to document the diagnoses, symptoms, treatments and health of people with Alzheimer's, dementia and other types of memory loss to spotlight early symptoms, patterns and potential treatments that may have been overlooked.

forMemory has established a database for this purpose. Databases containing information reported by patients have already been established for diseases like Parkinson's and endometriosis to help patients, doctors and researchers understand these diseases and develop new therapies. forMemory members believe this type of self-reported information will be useful in understanding memory loss.

You can help by participating in this database. For more information, contact Chris Baum VanRyzin, President of forMemory, at [cbvanryzin@aol.com](mailto:cbvanryzin@aol.com) or at 920-734-9638. You can also visit our web site at [www.forMemory.org](http://www.forMemory.org).

### **Should you take part in this project?**

This form provides information about the forMemory database. After reading through this form, and asking any questions you may have, you can decide if you would like to take part in the project.

### **Before you decide:**

- Read this form and make sure you know what the database is about.
- Talk about this database with a forMemory Board member (see above contact information). If you'd like, a care partner, friend or family member can also talk with board members.

### **This form explains:**

- Why this database is being developed.

Initials \_\_\_\_\_

- What will happen with the database and what you will need to do.
- How the information collected about you for the database will be used and with whom it may be shared.
- The confidentiality of the information collected for the database, and the steps forMemory takes to protect your privacy.

**You can ask questions:**

- You may have questions this form does not answer. If you do have questions, feel free to contact a forMemory Board member.
- You don't have to guess at things you don't understand. Ask the forMemory Board member to explain things in a way you can understand.

**After you read this form, you can:**

- Take your time to think about the information that has been provided to you.
- Have a friend or family member go over the form with you.
- Talk it over with your doctor.

**It's up to you. If you choose to participate in the database, then you should sign the form.** If you **do not** want to take part in this database, you should **not** sign the form.

**Why is this database being developed?**

This database is being developed to detect patterns in symptoms, possible treatments and overall health that may have been overlooked in studies of people with Alzheimer's, other dementias and memory loss. Developing the database will consist of collecting, storing, analyzing and distributing information so that people with memory loss, their friends and family and researchers can benefit from the information for personal or for research purposes.

**Why are you being asked to take part?**

We are asking you to take part in this database because you have experienced some memory loss.

**How long will you be asked to stay in the database?**

You will be asked to stay in the database as long as you can participate. The longer the period the database covers, the more patterns will become apparent.

**How often will you need to update your information?**

You will be asked to update your information once per year. A reminder will be sent out on or around the anniversary of the date you first participated in the database.

**How many other people will take part?**

At this time, the forMemory Board does not know how many people will take part.

**Will my personal health information be kept private?**

Data released to outside organizations will not include your name, your contact information or other personal information. Please see Confidentiality section below for details.

**Will you receive any information or results from this database?**

forMemory will publish a summary of the information in the database at least once per year on its web site, [www.forMemory.org](http://www.forMemory.org). This may also include information about the groups using the data. forMemory will try to seek cooperation with prospective study groups as to providing their general findings. There will be no individual feedback about the data you provide.

**How do you get started?**

If you decide to take part in this database, you begin by signing this form, which is your consent to take part in the database. A witness also needs to sign the form when you do. This form is also your agreement to allow us to use your personal health information as needed in the database. Until you have agreed to take part in the database and have signed this form, no data collection will take place. The form should be mailed to Chris Baum VanRyzin, 821 West Browning Street, Appleton, WI 54914.

**What will you need to do to get ready for participating in the database?**

You will need to read this form carefully, and ask questions if there's something you don't understand. You will also need a witness to sign the form when you do.

Using the questionnaire that will be sent to you upon receipt of this signed form, you will need to gather your information to be used in the database. You may need to refer to your medical records, your prescription containers and a calendar. You and/or your care partner will need to carefully consider each question on the questionnaire and write down the best answer available.

**Will you be paid for taking part in this database?**

No, you will not be paid to take part in the database.

**What will it cost you to take part in this database?**

There is no cost to take part in the database.

**What are the potential benefits if you take part in this database?**

Participating in the database has the following potential benefits for you:

- The process of completing the questionnaire requires that you think about your own experiences. This may bring unexpected insights about your

- memory loss.
- The forMemory questionnaire was developed from the symptoms, diagnoses, treatments and experiences of people with memory loss. In filling out this questionnaire, you may be able to discover potential therapies to discuss with your doctor.
  - You can take satisfaction from helping both people with memory loss and researchers learn more about memory loss.

**What are the disadvantages of taking part in this database?**

Gathering the information needed to fill out the questionnaire may take several hours of your time. You may need to ask your doctor for a copy of your medical records to complete the information, and your doctor may charge a fee for copies of your records.

**Confidentiality of Information Used in the Database**

By signing this form, you are permitting forMemory to use personal health information collected about you for research purposes. You are also allowing forMemory to share your personal health information with individuals or organizations other than forMemory who are involved in research on memory loss or related health conditions.

**Who will see the information that you provide? Who else can use and share this information?**

forMemory may make limited data sets available to outside organizations for research purposes. Data sets released to outside organizations will not contain your name, phone number, postal address or email address.

Research institutions wishing to have access to a limited set of the data stored by forMemory must apply in writing to the Board of Directors. Criteria for release of limited data sets to outside organizations will include the ability to safeguard privacy. However, once any information leaves forMemory, we cannot promise that others will keep it private. The limited data sets will not include your name, phone number, postal address or email address.

**How will my information be used?**

By signing this form, you are giving your permission to use and/or share your health information as described in this document for any and all research-related purposes. Your authorization (permission) to use your health information will not expire unless you revoke this authorization in writing.

We may publish what we learn from this database. If we do, we will not let anyone know your name. We will not publish anything else that would let people know who you are.

## Your Rights

You can refuse to sign this form. If you do not sign this form, you cannot participate in the database.

### How do I withdraw permission to use my information?

You can revoke (withdraw) this form at any time by sending a signed and dated letter to Chris Baum VanRyzin at the address given below, stating that you wish to withdraw your consent to participate in the database and for the use of your information in the database. If you revoke this form, it will tell forMemory that you do not want to continue to participate in the database and that you do not want forMemory to use or share your information anymore. If you revoke this form:

- You will no longer be a participant in the database.
- **We will stop collecting new information about you.**
- **The information that we have collected before you tell us to stop may already have been used or shared, or we may need it to complete and protect the validity of any research, so you cannot withdraw your consent to let us use information collected before you revoke this form.**
- To revoke this form, you must tell us in writing. Please write to:  
Chris Baum VanRyzin  
forMemory  
821 West Browning Street  
Appleton, WI 54914.

### How will you keep my information confidential?

We will keep the records of this database confidential by assigning each person a random number. Randomly generated numbers will be used instead of names. forMemory Board members and any individual or organization they contract with for data collection and storage will have access to the names associated with these numbers. Files associating names with these numbers will be password protected. ***If an Institutional Review Board at a research institution needs to see records containing personal information in order to approve any research using the data contained in the database, forMemory's Board of Directors will decide whether to allow access on a case by case basis.***

It is up to you to decide whether you want to take part in this database. If you want to take part, please read the statements on the next page and sign the form if the statements are true.

**I freely give my consent to take part in this database and authorize that my health information as agreed above, be collected/disclosed as part of this database.** I understand that by signing this form I am agreeing to take part in the database. I have kept a copy of this form for my files.

\_\_\_\_\_  
Signature of Person Taking Part in Database

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed Name of Person Taking Part in Database

\_\_\_\_\_  
Email Address of Person Taking Part in Database

\_\_\_\_\_  
Street Address

\_\_\_\_\_  
City, state and zip code

\_\_\_\_\_  
Signature of Witness

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed Name of Witness

After you and a witness sign this page, please initial all pages, **make a copy for your files**, and mail **all** pages of the original to:

Chris Baum VanRyzin  
forMemory  
821 West Browning Street  
Appleton, WI 54914.

Once we receive this signed consent form, we will send you the questionnaire and ID number you need to participate in the database.