



# **Alzheimer's Disease International**

*The global voice on dementia*

## **CLINICAL TRIALS - ENGAGING PEOPLE WITH DEMENTIA IN RESEARCH HOW CAN ADI HELP?**

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# The importance of clinical trials

- **Without clinical trials, there can be**
  - no better treatments,
  - no prevention and
  - no cure for Alzheimer's disease.
- **Scientists work constantly to find better ways to treat diseases, but improved treatments can never become a reality without testing in clinical trials with human volunteers.**
- **Today, at least 50,000 volunteers, both with and without Alzheimer's disease, are urgently needed to participate in more than 130 actively enrolling clinical trials about Alzheimer's and related dementias.**
- **Recruiting and retaining trial participants is now the greatest obstacle, other than funding, to developing the next generation of Alzheimer's treatments.**

# How can ADI Help



- **Clinical trial website**
- **Report**
- **Global Clinical Trial Working Group on Dementia/Alzheimer's Research**
- **Brochure**
- **Educate our member's associations about clinical trials**
- **Promote Community Lectures through ADI's societies**
- **Create a strong and active network for clinical trials within our associations**

# CLINICAL TRIALS WEBSITE

## *Proposed content*



- ***Overview of the content – some key points:***
  - General information on clinical trials for Alzheimer’s and dementia
  - Find a clinical trial or study – Locate a research centre near you
  - Learn more about participating
  - Volunteer opportunities in the world
  - Videos (with interviews with people who participate in trials) - testimonials
  - A site that will connect the patient/caregiver/physician directly with the ongoing trials – an individual will have the opportunity to review the clinical studies
  - Brief introduction of studies: Study name / company / purpose of the study
  - Links to other resources

# CLINICAL TRIALS WEBSITE

## *Proposed content*



- **Information**

- How medicines are developed and patient information (why do people participate)
- Physicians document on trials
- Explanation of ADAS-Cog and other endpoints
- General information about Alzheimer's disease and dementia (videos Aboutalz.org)
- Other dementias like FTD, LBD etc
- What is ADI
- Link to list of Alzheimer associations
- Brief overview work of WHO, OECD, G7

# Report on clinical trials in dementia



- **That report will be a vehicle to promote clinical research and to “push” governments to implement an international and a national strategy on clinical trials in order to:**
  - Increase referrals through the national health care systems
  - Create a national dementia registry
  - Create an official network of patients and caregivers
- **A report will help us to answer some “key” questions and understand some important issues. For instance:**
  - How effective and cost effective is to have a clinical research network within the National Health System? – The paradigm of NHS
  - Overview of regulations (Europe, USA, Asia, Australia)
  - How many people have dementia now and how many of them are participating in clinical research? Overview of the best practices to minimize that gap (through Systematic literature review of interventions & evidence based research).

# **Global Clinical Trial Working Group on Dementia/Alzheimer's Research**



## **Create a Global Clinical Trial Working Group on Dementia (GCTWG) – (ADI-WHO-academics)**

- **The GCTWG on dementia will be focused on five critical goals to improve:**
  - coordination and cooperation among the functionally diverse components of the current system, including industry, federal regulatory agencies, associations, clinicians, patients, caregivers.
  - prioritization and scientific quality by recruiting more people in Alzheimer's disease research and developing an open and transparent process for the design and prioritization of clinical trials that are science-driven and meet the needs of patient care.

# **Global Clinical Trial Working Group on Dementia/Alzheimer's Research**



- **standardization of tools and procedures for trial design, data capture, data sharing, and administrative functions to minimize duplication of effort, and to facilitate development of a shared infrastructure to support an integrated national and international dementia clinical trials network.**
- **operational efficiency by increasing the rate of patient accrual and reducing operational barriers so that trials can be initiated and executed in a timely, cost-effective manner.**
- **To discuss openly and extensively the ethical issues around this issue.**



- **Together**, ADI's community, the community of researchers, individuals and families, clinicians, and the **public can address barriers and improve the prospects for clinical trials in dementia.**
- By doing so, **the chances of finding ways to prevent or effectively treat Alzheimer's disease** as soon as possible can be greatly increased.



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