This proposal was submitted to a successful businessman whose recovery from post-stroke aphasia was a long, frustrating experience. He wanted a comprehensive review of the literature, as well as a review of existing facilities and approaches to language and speech rehab.

PROPOSAL FOR ----------

Submitted by:

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GOALS

Based on current reviews on post-stroke rehabilitation of aphasia, I will: identify institutions and experts involved in cutting-edge research that might have direct applications to speech rehabilitation; conduct a "needs assessment" survey through interviews with the experts to determine how best academic research and clinical application can move forward more rapidly.

I will also, identify and document possible ways in which an informed non-academic with a strong personal interest and resources could:

- facilitate communication among aphasia experts in diverse fields
- support research efforts in some as-yet-to-be defined manner
- convene an inter-disciplinary summit, perhaps in conjunction with a major association such as the National Aphasia Association, of experts with the focus on defining clear research goals that could be supported via a foundation or similar mechanism
- take advantage of other opportunities as they present themselves

METHODOLOGY

The focus will be on current research that shows promise, based on expert opinion. The following areas have been identified as major research directions:

- brain imaging

- psycholinguistic therapies and cognitive neuro-rehabilitation techniques
- computer-aided techniques
- pharmacotherapies

Major institutions and experts will be identified and contacted as required.

DATA SOURCES

DATABASES

Several recent, excellent review articles have been identified, along with the clinical practice guidelines from the U.S., the U.K., and Scotland. These articles obviate the need to re-do extensive manual and electronic searches. The following databases will be represented in the review articles, or additional research performed by this researcher.

- Allied and Alternative Medicine
- Applied Social Sciences Index and Abstracts
- CANCERLIT
- ClinicalTrials.gov
- Electronic Journals Online
- The Cochrane Library
- ERIC: Educational Literature
- Health Source Plus
- HealthSTAR: covers health care delivery literature
- Mediconf: Medical Conferences and Events
- Medline and MedlinePlus
- PsycINFO
- Cumulative Index to Nursing & Allied Health (NAHL)
- American Speech-Language-Hearing Association archival sources
- Index Medicus
- ECRI Healthcare Standards Database
- NIH Grants Database Center Watch (Clinical Trials)
- National Institute of Neurological Disorders and Stroke (National Institutes of Health)
- National Institute on Disability and Rehabilitation Research (NIDRR) Program Directory database (National Rehabilitation Information Center)
- Government Reports and Announcements Index (NTIS)
- Science Citation Index

OTHER INFORMATION SOURCES

- Broad ranging searches of World Wide Web using several search engines
- Sources of information on assistive technologies, which include the NIDRR Program Directory database as well as the Health Devices Sourcebook and Federal Research in Progress database
- Review of bibliographies/reference lists from peer-reviewed journals
- Newspaper Plus and specific major newspapers
- Review of materials available from relevant associations: National Aphasia Association, National Rehabilitation Information Center, National Stroke Association, Stuttering Foundation of America and so forth
- Searches of non-journal literature such as proceedings from organizations, summits, associations and gray literature — reports, studies, and so forth generated by private associations, government agencies, corporations
- Interviews with experts

Full copies of reports, articles, and so forth will be obtained in a timely manner wherever possible and stored until requested. These will form the basis for analysis of the state of knowledge on post-stroke speech rehabilitation. A bibliography of sources used and cited will be maintained.

MAJOR FOCUS

Once a reasonable summary of the current knowledge has been obtained, a concise summary will be written. The goal will be to delineate the areas of major knowledge and the progress in these areas.

The ultimate goal is to target the experts in several disciplines, in the U.S. and abroad, whose work is showing promise. Direct contact will be made via email, fax, letter, and telephone calls.

In addition to eliciting some idea of upcoming significant research from the experts, the focus will be on seeing what kinds of support would be most helpful:

> ……more money, matching grants; more public awareness; education of health care professionals; better clinical practice guidelines; more aggressive use of current diagnostic techniques and therapies; inter-disciplinary training needed; greater inter-disciplinary interaction; support for larger clinical trials; other…….

OPPORTUNITY

The question of how to best facilitate research into post-stroke rehabilitation is the one we wish to answer. At all times, the question will be, *What is the opportunity here for ----- to act in accordance with his long-time dreams?*

Having a summary of research, while interesting, is only the foundation for identifying the people whose work may form the basis for better diagnosis and treatment of post-stroke aphasia. Supporting these individuals and their institutions in some fashion, or providing a venue for exchange of expert information is the arena in which to act.

JUSTIFICATION FOR THE PROJECT BASED ON A SUPERFICIAL LITERATURE SURVEY

After spending several more hours examining research from the U.S. and other countries, I am more convinced than ever that a major opportunity to help coordinate and "cross-pollinate" is available for someone with a strong personal interest and resources.

Non-U.S. work on aphasia seems to be coming largely from the UK and Germany, some from Japan, Israel, France, and Russia. Work in the U.S. is coming from several major universities and the Veterans Affairs medical system.

The database listing current research funded by the U.S. government, FEDRIP (Federal Research in Progress) lists 128 studies examining a range of aphasia issues. The federally funded research reflects the interests of the agencies administering the grants, but includes a number of neuro-imaging studies as well as pharmacotherapy. This database is a useful way to identify active researchers and institutions in diagnosis, speech therapy, imaging and so forth who may not have published widely yet on their results.

The National Institute on Disability and Rehabilitation Research (NIDRR) Program Directory database from the National Rehabilitation Information Center lists initiatives as well as research projects on aphasia., including a multi-year project being conducted by the Rehabilitation Institute Research Corp. evaluating stroke rehabilitation tactics and strategies.

In addition, federally funded studies looking at how motor learning might impact overall brain reorganization are beginning. The question of how increased motor abilities might impact speech has not been examined to any degree. However, work on constraint-induced movement therapy for rehabilitation of limbs is very promising.

The "black box" of rehabilitation

The Cochrane Library reported a major survey of the speech and language rehabilitation literature (or the "black box" of rehabilitation as one French researcher calls it) current through July 1999. They reviewed decades of journal articles and isolated 60 studies that met certain experimental criteria and examined these in detail. Only 12 of the 60 were even suitable for their

review. And of these, most were "old with poor or unassessable methodological quality."

The Cochrane Review concludes:

> *"We could not determine whether formal speech and language is more effective than informal support.*
>
> *…..speech and language therapy for people with aphasia after a stroke has not been shown either to be clearly effective or clearly ineffective within a randomized control trial. Decisions about the management of patients must therefore be based on other forms of evidence…..if researchers choose to do a trial, this must be large enough to have adequate statistical power, and be clearly reported."*

Clinical guidelines—not evidence-based for the most part

I examined clinical practice guidelines for post-stroke care from the U.S. (Agency for Healthcare Research and Quality), the U.K. (Royal College of Physicians), and Scotland (Scottish Intercollegiate Guidelines Network.)

Unfortunately, the sections on communication disorders rely on "we think it is valuable to rehabilitate, but we aren't sure what really works" as evidence. Recommendations are largely based on consensus of experts, but not on evidence from randomized trials.

The Royal College of Physicians listed explicit guidelines:

> *Stroke can affect communication in different ways. The patient may have impaired motor speech production (dysarthria) resulting in unnatural or unintelligible speech; they may have impaired language skills (aphasia or dysphasia); or they may have impaired planning and execution of motor speech (articulatory dyspraxia). The patient may have subtle communication problems due to higher level language impairment associated with non-dominant hemisphere stroke. Untrained clinicians may misdiagnose the cause of abnormal communication. Accurate diagnosis is essential to guide and inform the team and the family. A speech and language therapist is the most competent person to assess a patient with abnormal communication.*
>
> **RCP Guidelines**
>
> a. *Every patient with a dominant hemisphere stroke should be assessed for dysphasia using a reliable and valid method* ***(C)***
> b. *Every patient with difficulties in communication should be assessed fully by a speech and language therapist (SLT)* ***(B)***

c. *If the patient has communication difficulties, the staff and relatives should be informed by the SLT of communication techniques appropriate to the impairment **(A)***
d. *Where achievable goals can be identified, and continuing progress demonstrated, patients with communication difficulties should be offered appropriate treatment, with monitoring of progress **(A)***
e. *Patients with specific communication difficulties should be assessed by a SLT as to their suitability for intensive speech and language therapy treatment which the trials suggest should be for a 4–8 week period **(B)***
f. *For patients with long-term language difficulties, especially with reading, a period of reading retraining should be considered **(A)***
1. *Any patient with severe communication disability but reasonable cognition and language should be assessed for and provided with appropriate alternative or augmentative communication aids **(C)***

CLM note: RCP used evidence rating based in U.S., Agency for Healthcare Research and Quality criteria — **A** = at least one randomized controlled trial as part of body of literature of overall good quality and consistency; **B** = availability of well conducted clinical trials but no randomized clinical trials; **C** = evidence from expert committee reports, opinions, or clinical experience of respected authorities.

According to U.S. guidelines, *Post-stroke Rehabilitation,* the following should be research goals for speech and language therapy:

- identify characteristics of patients most likely to benefit from rehabilitative interventions
- determine optimal type of rehabilitation program for different types of patients
- identify factors that affect optimal timing, intensity, and duration of rehabilitation
- determining effectiveness of specific treatments or combinations thereof, in reducing impairments
- develop and validate standardized tests for monitoring post-stroke rehabilitation

Brain imaging

Research from the UK using PET scans to examine recovery from aphasia confirms the importance of functional recovery of tissue near the area of stroke damage. Along similar lines, other research using PET scans (performed in Germany), has shown that the brain recruits right-hemispheric regions for speech processing when left-hemispheric centers were impaired. This wasn't an ideal outcome—repair of the original speech-relevant network lead to the best recovery. The British researchers comment that there is no

reason to assume that mechanisms of recovery are uniform among aphasic stroke patients.

This research, in addition to earlier work on the reorganization of the brain post-stroke, emphasizes the value of neuro-imaging for individual patients in order to insure proper diagnosis of the post-stroke speech deficits and subsequent therapy design.

Neuroscientists meeting at the National Academy of Sciences in April 1999 reviewed research developments during the Decade of the Brain (1990-1999.):

> *"Information gleaned from these new scanning techniques and other research is being translated into more effective diagnosis and treatment for a variety of disorders….a profusion of specialized systems seems to be largely set by the genome, but those systems are heavily influenced by individual learning and are surprisingly "plastic."*

The importance of individual differences cannot be overstated. One of the difficulties with assessing therapies is the marked differences between individuals given the same regimen.

Pharmacotherapy

The use of drugs has been largely limited either to stroke preventative measures or acute post-stroke therapies administered to reduce damage.

Using adjunct drug therapies to improve communication has a sound theoretical basis, but the experimental evidence has only recently stood up to the promise. The drugs are utilized with speech therapy and some of the most promising work is being done in Germany with piracetam to facilitate rehabilitation of post-stroke aphasic patients. Other drugs that have been tried include bromocriptine (Italy)—found helpful in high doses, vasopressin (Russia)—improvement in speech reported in 79% of cases. Other work has been done using amphetamines and serotonergic drugs (fluoxetine, trazadone and desipramine.)

Psychosocial issues

Recovery of speech—or any function—after traumatic brain injury or stroke also depends on the psychosocial setting in which the patient finds him or herself. It is not simply a matter of applying a therapy—there are major emotional factors that effect the outcome. Treatment of depression is considered a major post-stroke challenge.

Recent research confirms that permanent changes may occur because of stress. The brain itself may be damaged. The presence of stress-related

illness (post-traumatic stress disorder, chronic pain conditions and so forth) might greatly influence the efficacy of post-stroke therapies. No one has examined this a basis for differences in outcomes.

Health professional's views on care of stroke patients

An interesting British survey—which ought to be reproduced in other venues simply to strengthen what I believe reflects general attitudes—examined how health care professionals regarded their work with stroke patients.

- occupational therapists reported that they theoretically had lots to contribute but the lack of resources and staff shortages prevented them from fulfilling their potential
- nurses and physiotherapists reported they had much to offer and many rewards to gain from their work
- speech therapists reported scarce resources, lack of recognition of their specialty, but felt they contributed to patients' quality of life
- psychologists reported their work to be satisfying and stimulating
- **doctors felt they had little to offer and little to gain from working with people with stroke**

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