

Key Points

1. According to PubMed, there were 122 studies published in 2004 which at least mention Chiari and/or syringomyelia
2. Discounting citations that are incidental to CM/SM; nearly half of the publications were simple Case Reports
3. There were no randomized treatment studies; no studies on recovery; no studies on non-surgical treatments, and no studies on the psychological impact of living with CM/SM
4. In comparison, PubMed showed over 1,500 studies on Multiple Sclerosis across a wide range of topics
5. The US Government reported supporting only 3 studies having to do with CM/SM in '04
6. The good news is that research advances in imaging and nerve repair continue

Definitions

case study - type of research which focuses on one subject, or person, as opposed to a group of subjects

control group - in a study, a group of subjects who are used as a basis for comparison; the control group is usually healthy, or does not receive a treatment that the experimental group receives

CRISP Database - Computer Retrieval of Information on Scientific Projects ; searchable database, maintained by the National Institutes of Health, which contains all Federally funded biomedical research projects

hypothesis - a proposed idea, not yet tested, about how or why something works

Multiple Sclerosis - serious, chronic, neurological disease, where for reasons unknown, the covering of nerve fibers are destroyed, disrupting the normal nerve activity

Year In Research: 2004

Maybe ten or twenty years from now Chiari & Syringomyelia News will be able to report that 2014 or 2024 was an exciting, banner year for research, filled with stunning insights and major breakthroughs. Unfortunately, we are unable to report this for 2004. Like its predecessors, 2004 was an average year for Chiari research, which means there were relatively few publications, dominated by Case Reports, and there was little measurable progress in improving the experiences of patients.

Despite this publication's strong desire to report better news, we must point out that 2004 did NOT bring about any significant new treatments, did nothing to unify the many different views held by neurosurgeons, and did not even address numerous issues that Chiari and syringomyelia patients deal with on a daily basis.

According to the National Library of Medicine, what 2004 did bring was 122 publications on Chiari and/or syringomyelia (see Table 1). Unfortunately, 20 of these simply mentioned Chiari or SM, and did not really focus on them. Of the remaining publications, nearly half (49) were Case Reports. While Case Reports - which simply report the medical details of one or two patients - can be interesting, they do little to advance the scientific cause.

Table 1
2004 PubMed CM/SM Citations By Subject Type (122 Total)

Subject	# of Citations
Incidental Reference	20
Case Study	49
Surgical/Results	11
Animal	6
MRI/CSF Flow	6
Reviews	5
Theoretical	4
Chiari II	4
Symptoms	4
Scoliosis	3
Pain	2
Posterior Fossa Volume	2
Arachnoid Veils	1
Post-traumatic SM	1
Fibromyalgia/CM	1
Endocrinology	1
Idiopathic SM	1
Self-report	1

- Incidental refers to a study which mentions Chiari or syringomyelia in passing, but CM/SM is not the focus of the publication
- Reviews refer to papers which simply summarized current knowledge, but did not report any new data or ideas
- Case studies refer to publications which report on 3 or fewer patients and are mostly descriptive in nature

In fact the most rigorous type of scientific study, prospective, randomized, controlled trials, were once again conspicuously absent in the Chiari research. Outside of the Case Reports, there were 11 articles published dealing with surgical outcomes and/or technique; however, there were no direct comparisons of one technique versus another. Rather, the Chiari research - much like in previous years - tended towards individual surgeons reporting their results for a group of patients, as opposed to rigorously designed trials.

While the publications did cover topics ranging from new theories on syrinx formation to when scoliosis might

prospective - type of study where the experiment is designed before the data is collected

PubMed - database maintained by the National Library of Medicine, includes over 15 million citations for biomedical articles

randomized - technique used in a scientific study where participants are randomly assigned to one of two groups; used to control the effects of age, gender, etc. on the study outcome

retrospective - type of scientific study which looks back in time, often at medical records

review - type of publication which summarizes the current knowledge on a given subject; usually does not provide new data or hypotheses

Source

PubMed search with keywords Chiari, syringomyelia and limit of publication date between 1/1/04 and 12/13/04. Duplicate results were eliminated manually. Citations were categorized by the editor.

indicate Chiari, there were no reports on non-surgical treatments, no publications on recovery issues, no articles on the psychological impact of CM/SM, and very little work on the many issues that arise as a result of living with these diseases.

The good news is that progress was made in some areas. Work using advanced imaging technologies continued to show promise, and as this issue reports, some researchers are beginning to focus on the importance of compliance as a measure of both the impact Chiari has and of surgical success.

In addition, areas of study peripheral to CM/SM - namely nerve regeneration and pain control - advanced at a rapid pace. Spurred on by the attention - and money - that Christopher Reeve brought to paralysis research, several ideas for regrowing nerves are beginning to show promise. On the pain front, despite the withdrawal of Vioxx, the drug companies continue to pour millions into developing new pain medicines. As a community, we can only hope that some of the work in these areas will translate directly into helping people with CM/SM.

While there is always reason to hope, it is important to put the state of Chiari research into perspective. In previous articles, this publication has used Multiple Sclerosis as a basis for comparison. Unfortunately, from the research point of view, there is no comparison. According to PubMed, there were over 1,500 articles published on MS in 2004; more than 10 times the number of Chiari articles. It's not just the quantity of work that is different either; the first 20 MS citation results (from a PubMed search) showed structured, randomized trials, plus research into new treatments, recovery issues, and living with MS.

Why is there such a large disparity between MS and Chiari research? The short answer is money. The National MS Society alone sponsored \$35 million dollars of research in 2004 and launched 115 new projects. The dollars came from the US government as well. According to the National Institutes of Health's CRISP database, there were 409 federally funded projects focusing on MS in 2004. During the same time period, there were 3 federally funded projects on Chiari and/or syringomyelia. One project involving an NIH researcher, one project on Fibromyalgia and Chiari, and one project which involved spina bifida. Compared to the dollars spent on MS - both public and private - the money spent on CM/SM is barely a drop in the bucket.

While the short answer is money, the reality is more complex and has a lot to do with well organized advocacy groups. For years, the MS community has been very vocal in not only raising awareness (which translates to donations and to private research funding) but also in focusing NIH dollars on their cause. If the Chiari and syringomyelia community ever hopes to make real progress on the research front and improve the lives of patients, it must come together in raising awareness, raising money for research, and raising it's voice to the NIH. Maybe then, Chiari & Syringomyelia News will be able to report on a great year in research.

--Rick Labuda

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