

The Savant Syndrome Registry: A Preliminary Report

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ABSTRACT

A registry has been established to document certain characteristics on a sizeable worldwide sample of individuals with savant syndrome, a rare but remarkable condition in which persons with developmental disabilities, brain injury, or brain disease have some spectacular “islands” of skill or ability that stand in jarring, marked contrast to overall handicap. Of the 319 savants included in the registry, 90% are congenital savants, while 10% are acquired savants. The registry includes individuals from 33 countries, with 70% from the United States or Canada. Sex distribution was 79% male vs 21% female (4:1).

This report summarizes the findings in the congenital savant syndrome category of the registry. Among the individuals with congenital savant syndrome, the most common underlying disability was Autistic Spectrum Disorder (75%); various other central nervous system (CNS) disorders were present in the other 25%. Fifty-five percent possessed a single special skill, while 45% had multiple skills. Music was the most frequent principal skill followed by art, memory, mathematics, calendar calculating, language, visual-spatial/mechanical, athletic, computer, extrasensory perception, and other skills.

BACKGROUND

Savant syndrome is a rare but remarkable condition in which persons with developmental disabilities, brain injury, or brain disease have some spectacular “islands” of skill or ability that stand in jarring, marked contrast to overall handicap. The condition can be present from birth or surface in early childhood (congenital) or can surface unexpectedly following head injury, stroke, dementia, or other central nervous system (CNS) disorders (acquired). The special skills occur most commonly in the areas of music, art, calendar calculating, lightning calculating, or mechanical/spatial abilities. Whatever the special skill, it is always accompanied

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by extraordinary memory of a particular type—very narrow but very deep within the area of special ability. It occurs much more frequently in males than females in an approximate 4:1 or 6:1 male to female ratio, depending on the study.¹

In his lecture and book in 1887, JL Down used the term “idiot savant” for this juxtaposition of ability and disability within the same person.² The term had appeared previously in a book by E Seguin.³ At that time, “idiot” was a scientific classification of people with an IQ below 25, and the term “savant” was derived from the French word *savoir*, meaning “to know or knowledge able person.” Because of the pejorative connotation of the word “idiot,” Treffert suggested in 1988 that the condi-

tion be named savant syndrome,⁴ and the term has been in general use since then.

Previous Reports of Savant Syndrome

Since those earlier descriptions, the vast majority of documented cases of savant syndrome have stemmed from anecdotal reports of individual cases. A survey of the literature between 1898 and 1974 by Hill⁵ found 52 individual savant case reports. Savant skills in those cases fell into 7 general areas: calendar calculating, fine sensory discrimination, art, mechanical dexterity, music, mathematics, and memorization of obscure facts—in that order.

In 1977, Hill canvassed 300 public residential facilities for the mentally retarded in the United States⁶ asking the superintendents to indicate how many savants had been identified in their programs. There were 111 responses from facilities serving approximately 90,000 residents in 39 states. A total of 54 individuals with savant syndrome were, or had been, residing in 23 facilities, creating a prevalence rate of approximately 0.06% (approximately 1 per 2000 residents).

The following year, Hill reported that of 103 individuals classified as savants in 63 publications, 89 were male and 14 were female—a 6:1 male to female ratio in that group.⁷

Also in 1978, Rimland published findings from a questionnaire given to parents of 5400 children with autism.⁸ The responses indicated that 531 children had special savant syndrome abilities in 10 skill areas: music, memory, art, pseudo-verbal (hyperlexia), mathematics, mechanical, coordination, directions, calendar calculating, and extrasensory perception—in that order. The male-to-female ratio was 3.54:1. It is this study that provided the generally accepted figure that 10% of autistic children show some savant abilities.

In a 2000 survey in Finland of 583 inpatient or residential facilities with a total patient population of 31,300, Saloviita and colleagues⁹ found 45 individuals with savant abilities—an estimated 1.43 per thousand among people with intellectual disability. That rate is nearly double the rate of the 1977 Hill study noted above. Of the 45 savants, there were 35 men (78%) and 10 women (22%). Calendar calculating ability was particularly common (62%), followed by skills in memory (29%), art (13%), music (7%), mechanics (4%), and mathematics (2%). Multiple skills were present in 16% of that group, most often linking calendar calculation with memory skills.

In 2004, Bolte and Poustka¹⁰ reported 33 persons with savant syndrome out of a group of 254 individuals with “idiopathic autism”—a prevalence of 13%. Howlin et al reported in 2009 that 39 of 137 individuals with autism (28.5%) met their criteria for savant syndrome based on cognitive testing and parental reports.¹¹

In contrast to these earlier anecdotal reports and smaller samples, our registry consists of 319 individuals with savant syndrome and provides a detailed analysis of type of disability, type of ability, frequency of particular skills, age, sex, geographic location, and a number of other variables. This report summarizes the findings in the congenital savant syndrome category. Results of the acquired savant syndrome category will be summarized in a later report.

Establishing a Savant Syndrome Registry

After reviewing those earlier single case reports and limited samples, it seemed useful to establish a larger, worldwide savant syndrome registry that would permit analysis of a larger sample of savants on a number of variables for research, education, and information purposes. It also could serve as a resource of cases for other researchers using multidisciplinary imaging, neuropsychological, genetic, and other techniques and carrying out epidemiologic analysis of savant syndrome.

The registry had its beginnings in 1984 when Alonzo Clemons, a savant sculptor, had his world premier exhibition of 30 bronze sculptures in Denver, Colorado. Alonzo was 1 of 3 savants featured in an October 1983 *60 Minutes* program that gave savant syndrome its first worldwide television exposure. A portion of the proceeds of that exhibition went to the Wisconsin Medical Society Foundation to establish an information and education

clearinghouse dedicated to raising awareness of, and education about, savant syndrome for parents, other caregivers, teachers, clinicians, media, and the general public.

Initially the clearinghouse operated using regular mail, printed reports, and press releases.

Simultaneously, reports of various savants from around the world came to the attention of the clearinghouse. Those were simply put into a folder for future reference. In fall 1987, a website—www.savantsyndrome.com—was established by the Wisconsin Medical Society as a much more efficient, instant, and effective manner of conducting the clearinghouse function. In 1989, the movie *Rain Man* made “autistic savant” household terms and traffic on the website increased dramatically. Currently, the website is ranked highly on many search engines worldwide and receives over 500 hits daily from parents, clinicians, teachers, media, students, and many others.

Web-based recruiting for health research, as used here, as a source of case reports or subjects is growing, including patient self-reports through social networking.¹²

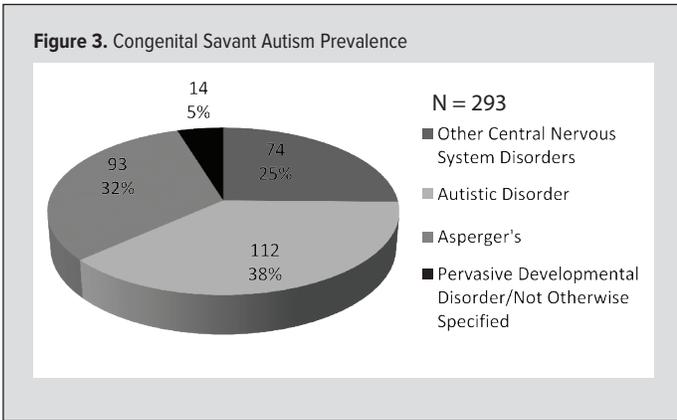
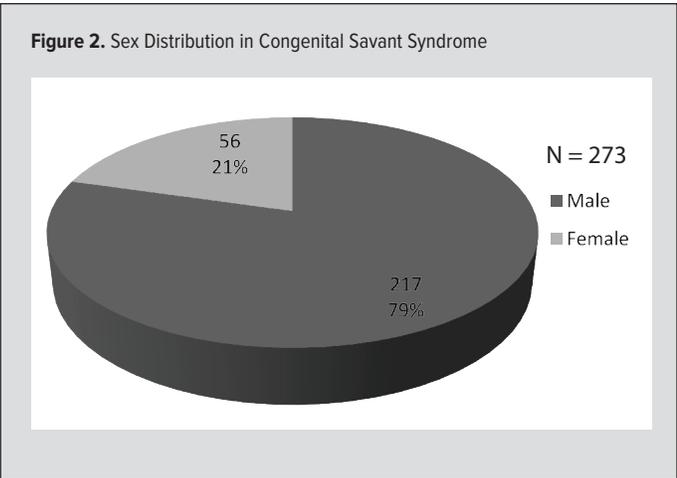
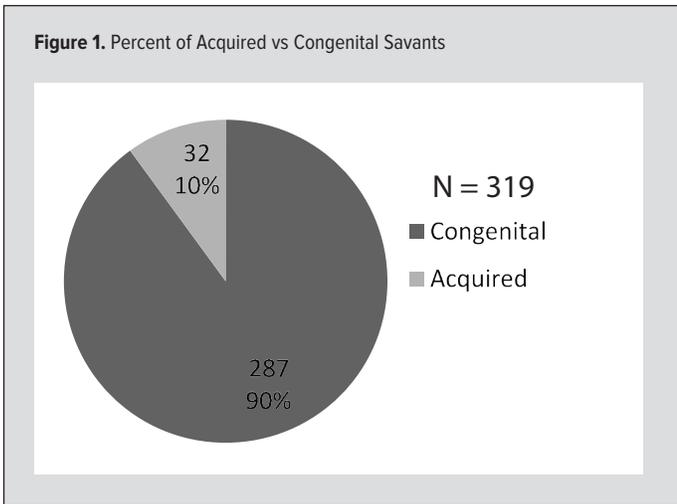
By 2012, the folder of new savants from various sources had grown to nearly 400 cases. In summer 2012, a summer research fellowship was awarded to a medical student (Rebedew) for purposes of organizing and analyzing the data in the case reports. This paper is a preliminary summary of that registry from 1984 to 2012.

This registry has its limitations. It contains unsolicited cases brought to attention in a non-uniform manner. Therefore, it does not provide an estimate of the prevalence of savant syndrome worldwide, nor the prevalence of savant syndrome within certain disorders such as autism or other developmental disorders, for example.

The cases rely on parental accounts or reports of other caregivers, media accounts or, in some cases, personal observation. They are not formally corroborated, but the reports appeared reliable, often supported by accompanying videos or other documentation. This circumstance is similar to almost all of the earlier reports described in the literature, including Rimland’s sample of 530 savants.⁸

While to some caution is warranted regarding the mention of extrasensory perception, in Rimland’s sample as well as this one, some parents listed such phenomenon. Mentioning that such phenomenon are reported by others in this and other studies of savant syndrome is not the same as corroborating or documenting their validity. Rather, it merely acknowledges that extrasensory perception continues to surface in some studies of savant syndrome. Since extrasensory perception is mentioned quite frequently in the broader autism literature in general, there are studies underway to document or refute such phenomenon.

Finally, this is a preliminary report and identified as such. The next step—already underway—is to ask the sources in this study



to complete an especially constructed, detailed, standardized questionnaire administered using SurveyGizmo Online Questionnaire Software. Replies to this 94-question online instrument will provide more detailed, standardized information with a uniform “n” for all the variables being monitored for all the savants. Additionally, discussions are underway to continue and expand the savant syndrome registry by combining it with an already functioning synesthesia registry with the University of Sussex in England.

METHODS

Subjects for the current study were chosen based upon existing mail and e-mail inquiries from the savant syndrome website at www.savantsyndrome.com, media articles, and personal contacts (N=367). Variables including name, address, date of birth, sex, ethnicity, type of disability, congenital vs acquired etiology, age of onset of disability, IQ level, type of ability, schooling, occupation (if applicable), treatment, progress, family history, parental education level, and parental occupation, to the extent each of these variables were available from each subject, were entered into Microsoft Excel for analysis. Because some reports did not include all variables (ie educational level), the “n” for some variables differed from the total study population.

If the individual’s sole ability consisted of synesthesia, hyperlexia, or high intelligence, he or she was excluded from the current data set (n=4). If the individual did not have a disability, he or she was excluded from this study since savant syndrome, by definition, includes some underlying disability on to which the special savant skill is grafted or superimposed (n=44). After the exclusion process, data for 319 individuals was categorized and analyzed. Individual handicaps were listed according to reported diagnoses.

Principal ability was a subjective determination based on information contained in the various reports. All abilities were then categorized into music (performance, perfect pitch, composition, memory for music), art (drawing, painting, sculpting), memory (facts, numbers, dates, photographic, hyperthymestic), lightning calculating (ability to do complex multiplication, division, and/or exponentials mentally), calendar calculating (knowing on which day of the week a date in the past or future falls), math truths (having an understanding of complex mathematics at a very early age and knowing multiple digit prime numbers), language (being able to learn a new language fluently and quickly, able to speak multiple languages with no accent, proofreading papers with little effort), visual-spatial (able to take apart and put back together complicated mechanical devices, perfect sense of direction and global positioning system-like recall of directions, being able to measure distances or heights with precision), athletic (a very skilled level of golf, basketball), computer (writing programs, coding, learning new computer languages), and extra-sensory perception (mind reading, telepathy).

RESULTS

After the exclusion process detailed above, data on 319 savants was available for analysis. For some variables, data was available on all 319 individuals. For other variables, such as age, educational level, or ethnicity, data was available on less than the entire sample. Therefore the “n” for some variables is less than 319.

Congenital vs Acquired Savant Syndrome

Savant syndrome can be *congenital* or *acquired*, and it is not a

stand-alone condition. Rather, the special savant skills are always grafted on to some underlying disability that can include, but is not limited to, autistic spectrum disorder (ASD). For purposes of this study, congenital savant syndrome means savant skills present from birth or emerging in early childhood with conditions such as early onset and late onset ASD, other developmental disorders, intellectual disability, Williams syndrome, agenesis of the corpus callosum, tuberous sclerosis, hypopituitarism, or other brain disorders as the underlying disability. Acquired savant syndrome refers to savant abilities that emerge, sometimes at a prodigious level, in a previously neurotypical child or adult following head injury, stroke, dementia or other CNS incident. Using those definitions, Figure 1 illustrates the congenital/acquired ratio.

Sex Distribution

Sex distribution among those with congenital savant syndrome is approximately 4:1, male:female. (Figure 2.)

Primary Disability in Congenital Savant Syndrome

Seventy-five percent of individuals in whom savant syndrome was present in childhood had an autism-related condition as the underlying disorder. Twenty-five percent had other developmental disabilities or other CNS conditions as the underlying disorder, including intellectual disability, Williams syndrome, agenesis of the corpus callosum, tuberous sclerosis, and hypopituitarism. That is not surprising since, as noted above, approximately 1 in 10 children with autism have savant syndrome, whereas that number drops to 1 in 1400 in other CNS disorders. (See Figure 3.)

Single or Multiple Abilities in Congenital Savants, Principal Skills

Among congenital savants, 55% have a single skill and 45% have multiple skills. Music is the most commonly reported principal skill in congenital savants, whether the savant had single or multiple skills. Art is the second most common. If memory is considered the principal skill (as opposed to only accompanying a skill), it is the third most common skill followed by mathematics. Calendar calculating, while present in many savants along with the principal skill, was reported as the principal skill in only 5% of savants. Other skills, in descending order of frequency were polyglot (language), visual-spatial, athletic, computers, and extrasensory perception. (See Table 1.)

Geographic Distribution of Savants

Thirty-three countries are represented by savants included in this registry, with 70% from the United States and Canada. Fifteen percent are from Europe; 11% are from Asia (Table 2).

DISCUSSION

This study of savant syndrome abilities does not measure the frequency of such special abilities in autism or other CNS disorders. Rimland's 1978 questionnaire of parents still provides

Table 1. Principal Skill in Congenital Savants (N=281)

Music (performance, composition, perfect pitch, memory)	25%
Art (drawing, painting, sculpting)	19%
Memory (facts, numbers, dates, photographic hyperthymestic)	20%
Mathematics (lightning calculating, exponentials, truths)	11%
Calendar calculating (day of week for past or future dates)	5%
Language (polyglot skills in learning or speaking language)	4%
Visual-spatial/mechanical (maps, directions, how things work)	8%
Athletic (golf, basketball, soccer)	3%
Computer (programming, coding)	2%
Extrasensory perception	1%
Other	2%
	100%

Table 2. Geographic Distribution of Savants (N=204)

North America, n = 155	
USA	142
Canada	13
Europe, n = 26	
United Kingdom	18
France	5
Germany	3
Asia, n = 14	
China	2
India	8
Japan	2
Singapore	2
Other, n = 9	
Australia	7
Brazil	2

the largest population sampled (5400 children), of which 531 (approximately 10%) reported such savant abilities.⁸ Other studies reported savant syndrome prevalence ranging from 13%¹⁰ to as high as 28%.¹¹

Since the early description of savant syndrome over 100 years ago, most of the special skills have been in 5 categories: music, art, calendar calculating, lightning calculating, and visual-spatial/mechanical skills. While it is true that these skill areas still dominate the inventory of abilities, this broad-based review shows that savant skills can include many other skills as well, such as language, computer, athletic, and extrasensory abilities. Some savants have extraordinary memory as their principal skill, but increased memory capacity generally accompanies the principal savant ability.

In this report, the male-to-female ratio was 4:1, which is slightly less than some other earlier reports.

While the movie *Rain Man* left the impression with some that autism and savant syndrome were always linked, the fact is that not all people with autism are savants, and not all savants are autistic. In this study, autistic spectrum disorder was the underlying disability 75% of the time, while other CNS disorders are present 25% of the time. In addition, 10% of the savants were

“acquired” savants with various CNS injury or disease the underlying acquired disability.

The data for this registry was from various sources as opposed to a questionnaire with standardized variables. As the next step in developing the savant syndrome registry, a more uniform, systematic, detailed follow-up questionnaire was created using SurveyGizmo Online Questionnaire Software. This 94-question online survey was sent to the parent, caregiver, or savant. Results will provide much more detailed data for analysis on many more variables than this preliminary report, with a uniform “n” for each variable.

CONCLUSIONS

An analysis of 319 individuals with savant syndrome drawn from a variety of sources produced the following results:

- 90% were congenital savants; 10% were acquired savants.
- The savants identified were from 33 different countries, 70% were from North America.

Among congenital savants:

- Gender distribution was 4:1, male to female.
- Underlying disability was autistic spectrum disorder in 75% of cases with various other CNS disorders in 25% of cases. Thus, not all persons with autism are savants and not all persons with savant syndrome are autistic.
- Music was the most common savant skill, followed by special skills in art, memory, mathematics, visual/spatial/mechanical, calendar calculating, language (polyglot skills), athletic, computer, and extrasensory perception.
- Single skills were present in 55% of cases; multiple skills were present in 45% of cases

Separate analysis studies will be carried out on the acquired savant, and a comprehensive standardized survey instrument will be sent to each of the 319 individuals included in the registry for a more comprehensive, multifactorial analysis.

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