NeuroSurvey: A Report on Awareness and Advocacy for Pediatric Neurological Conditions

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-The creation and distribution of the Neurosurvey, and writing of the following report, are dedicated to Jacob George and Palmer Clay Richmond; their boundless optimism has inspired us all.
Abstract

In the United States, over 14 million children, roughly 5% of the population, suffer from Pediatric Neurological Conditions (PNCs). Researchers from the Pediatric Brain Foundation, in an attempt to shed more light on this important issue and catalogue some information regarding awareness of PNCs, disseminated a survey to the Central New Jersey area, known as the NeuroSurvey. The follow-up analysis on the results of the aforementioned survey are contained within this report. The NeuroSurvey specifically focuses on responses from individuals of high-school and college age, and then further analyzes these results to evaluate awareness and propensity for PNC advocacy through a multitude of areas including, but not limited to, knowledge of conditions, media representation, and political advocacy. Although most respondents were more likely to take up advocacy after being exposed to someone with a PNC and nearly 68% believe that more representation is necessary in the media, most respondents (90%) were not familiar with the vast majority (24 of 30) PNCs, exposing large gaps in the scope of awareness. In general, individuals are willing to learn more and in turn, advocate, but lack simple and convenient methods for increasing the knowledge needed to advocate.
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Section I: Introduction

Background Information
An article published by the University of California San Francisco Medical Center (2015) defines a neurological disorder as a "[disease] of the brain, spine and the nerves that connect them” and notes that there “are more than 600 diseases of the nervous system”. In the United States, over 14 million children suffer from these disorders, according to a fact sheet published by the Pediatric Brain Foundation (2015), a figure roughly equal to 5% of the population. Some of these conditions are congenital, or acquired at birth, while other conditions may develop later in child’s life (ucsfbenioffchildrens.org, 2015). Despite differences between the various types of Pediatric Neurological Conditions, a fact sheet published by the United States National Library of Medicine (2014) explains that when something is functioning incorrectly with a part of the nervous system, the problems that ensue can include difficulty moving, speaking, swallowing, breathing, or learning, as well as negative changes to memory, senses or mood.

Purpose
A two-fold purpose exists for the NeuroSurvey. First, utilization of a case-study format helps gauge awareness regarding the issue of Pediatric Neurological Conditions in one geographical area. Furthermore, analysis of data across small cross-sections of the population will determine more clearly how individuals acquire information about Pediatric Neurological Conditions. This in turn, will reduce difficulties in assessing how to best increase advocacy for this important issue.

Methods
Data was collected via dissemination of an online survey through social media websites, including Facebook and Twitter. The younger segment of the population, including high-school and college aged individuals were the main focus for this survey. Facebook and Twitter are employed because the younger, target segment of the population can access these methods conveniently and often, and in fact, do so. A flyer designed to increase responsiveness to the survey, along with the survey itself, are designated within the Appendix.

Within the survey, several factors are addressed, including knowledge of Pediatric Neurological Conditions, identification of condition names, methods of learning about such conditions, personal connections to those with a Pediatric Neurological Condition, representation of Pediatric Neurological Conditions in the media, and how a policymaker’s stance on funding science affects support for said policymaker. A spreadsheet containing the raw data is attached in the Appendix.

Responses were garnered from over 230 individuals, mostly in the Central New Jersey area. Descriptive statistical methods were used to clarify basic trends regarding awareness of Pediatric Neurological Conditions in Section II. Correlational data and hypothesis testing were also utilized in Section III to extract cross-variable relationships and draw conclusions regarding potential variables that can increase awareness and advocacy.
Limitations
Due to convenience sampling, only one segment of the population was potentially sampled by the survey, those likely to respond to a request to complete a survey. However, it is unclear whether this “convenience-sample” of individuals would proffer different responses to a survey specifically about PNCs than the general population.

Whether respondents’ answers represented their true thoughts on the issue was impossible to verify, naturally limiting the survey format. Awareness could potentially have been exaggerated or feigned because respondents may have felt embarrassment if they experienced a low level of awareness. Specifically, it’s anticipated that Figure 12 and Figure 13 may suffer especially from this limitation, in that respondent’s may first submit a confidence level, and then modify the number of conditions they knew in order to match that confidence level, over-estimating the number of conditions that a respondent actually knew. Concern about this issue can be minimized primarily by the fact that the survey required no identifying information whatsoever, hopefully alleviating respondent’s fears of being identified with their responses.

High-school and college age students were primarily targeted by this study, as mentioned before. This demographic for the most part, either isn’t able to vote or oftentimes, chooses to participate little in the political process. As few as 1 in 5 choose to vote (K, 2014). Thus, it becomes difficult to extricate information regarding actual voting patterns, especially when analyzing Figure 8, which asks respondents for the implications of PNCs on political support.

The difference between confidence level and awareness doesn’t indicate depth of awareness about one condition. For example, someone who indicated a 10 could just know a lot about just autism, for instance, and have a very little understanding of other conditions. This would significantly skew data because in reality this individual does not qualify as a very confident as per the definition held by this survey. When creating the survey, the definition of confidence used measured an individual's knowledge of all or a majority of PNCs, rather than just an extensive knowledge of just one.
Section II: Descriptive Data

In this section, survey results are disclosed in graphical and tabular form. This data assists in developing the full scope of the survey.

Figure 1: Which state are you from?

Central New Jersey represented the area with the most responses.
Figure 2: On a scale of 1-10, how confident do you feel about your awareness and basic knowledge of Pediatric Neurological Conditions in general?

A low level of confidence was indicated by most respondents. The mean confidence level found was 3.726 out of 10.
Figure 3: Which of these Pediatric Neurological Conditions are you aware of and have basic knowledge about?

Conditions including Autism, Down Syndrome, Epilepsy, Fetal Alcohol Syndrome, Stroke, Tay-Sach’s Disease, and Spinal Muscular Atrophy are demonstrated by the graph above to be chosen most by respondents. Within media and schools, these conditions experience a far more visual representation than the other conditions, suggesting a potential reason for this uneven representation effect. After examining these conditions, knowledge regarding the other conditions drops precipitously amongst respondents.
Figure 4: Do you know anyone who is affected by a Pediatric Neurological Condition?

It was indicated, to the best of the respondents knowledge, whether they knew anyone personally with a Pediatric Neurological Condition. 73.9% indicated yes, while 17.9% indicated no. Around 8.1% (19 respondents) indicated that they were unsure whether they knew someone with a Pediatric Neurological Condition.
Figure 5: How have you learned about Pediatric Neurological Conditions in the past?

The venues by which individuals accessed information regarding PNCs was assessed. Knowledge of Someone Affected (53.8%), Internet and Social Media (52.1%), the Education System (47.4%), or through Other Methods (42.7%) were the venues most popular amongst respondents. Note that respondents were allowed to choose more than one response.
Figure 6: How well are Pediatric Neurological Conditions represented in the media?

This question asks respondents to assess media representation of Pediatric Neurological Conditions. As is clear from the chart, most respondents, a total of 68.4%, responded with either a 1 or 2.
Figure 7: Where do you primarily consume media related to Pediatric Neurological Conditions?

Media consumption preferences for respondents were collected by this question. Utilizing this data could assist in the use of targeted, informative media being spread through the more popular avenues, such as internet blogging and sharing, or Facebook. Similar movements, such as the Ice Bucket Challenge, have gained popularity through these methods.
Figure 8: When considering legislators and policymakers, does their stance on funding science and drug development factor into your support?

It can determined whether a high level of interest or support for Pediatric Neurological Conditions as an apolitical cause can have prevailing influences when respondents choose politicians by using the data from this question. Overall, a large plurality of individuals (47%) indicated that policymakers stance on scientific funding was a factor in their support or opposition.
Figure 9: The Pediatric Brain Mapping Project is our initiative to identify all children living with more than 600 different pediatric neurological conditions. Would you like to be added to the Map as an advocate?

The number of respondents willing to be added and identified as an advocate for Pediatric Neurological Conditions was measured by this question. Unfortunately, most respondents indicated an unwillingness to advocate for those with Pediatric Neurological Conditions.
The total number of conditions each respondent was familiar with was calculated by utilizing the raw data from the survey. 6.5 conditions out of the 30 conditions represented the average number of conditions known, with most of these conditions known by the average respondent being concurrent with the list of “well-known” conditions in Figure 3.
Section III: Analytical Data

In this section, cross-variable relationships in the data (n = 235) are elucidated.

Figure 11:
Respondents’ confidence level regarding their knowledge of Pediatric Neurological Conditions and confidence level variance in response to either knowing or not knowing someone afflicted by a Pediatric Neurological conditions is measured in Figure 11. The histogram portrays two separate regions; on the right, those who knew someone with a pediatric neurological condition (Yes), and on the left, those who did not (No). In each region, the count of respondents who indicated each confidence level of 1-10 in each subgroup of either “Yes” or “No” is visualized. As is clear visually, despite the fact that several respondents knew someone with a Pediatric Neurological Condition (“Yes”), several of them still indicated little confidence regarding their knowledge of Pediatric Neurological Conditions.

However, in order to grasp more definitively the difference in confidence between those who knew someone with a PNC, the mean confidence level was averaged for those in the “Yes” subgroup, as well as those in the “No” sub-group. The mean confidence for those in the “No” sub-group was 3.262 while the mean confidence for those in the “Yes” sub-group was 3.890, with both numbers on a ten-point scale. Contradictory results to the previous paragraph do emerge when this difference is statistically analyzed. This is due to the fact that those in the “Yes” subgroup vastly outnumber those in the “No” subgroup. Indeed, when conducting a 1-tailed t-test between the mean confidence level of the two groups (those who knew others with a PNC, and those who did not) the resulting p-value was 0.0268. Naturally, the mean confidence level of those who did not know anyone with a Pediatric Neurological Condition was utilized for the null hypothesis ($\mu = 3.262$), while the mean confidence level for those who did know someone was used for the alternative hypothesis ($\mu = 3.890$). Comparing this to a benchmark of $\alpha = 0.1$, or even a benchmark of $\alpha = 0.5$, the result is statistically significant, indicating that there is a greater than 95% chance that the differences in confidence level amongst the aforementioned sub-groups is not due to chance.
Here, the link between a respondent’s stated confidence level and the number of PNCs that they were familiar with is analyzed. Respondents in each confidence level were grouped together as a bin. Within the bin, average numbers of conditions known were calculated. As the confidence of a respondent increases, so too, generally, does the number of neurological conditions that the same subject is knowledgeable about. For instance, those who indicated a confidence level of “2” were familiar with an average of 5.741 conditions, while those with a confidence level of “8” were familiar with an average of 11.500 conditions.
Figure 13

These data specifically extend the analysis presented in Figure 12. Here, each confidence-level bin on the 1-10 scale is still associated with the mean number of conditions known by the individuals within that subgroup. However, in this case, the conditions which individuals can potentially be familiar with were limited to conditions in which less than 10% of individuals, or 23 respondents, were originally familiar with, as shown by Figure 3. Familiarity with “lesser known conditions” was assessed for individuals in each confidence level bin. It was critical to reveal if those who had indicated a high level of confidence also had broad-based knowledge about many of the conditions revealed in the survey. However, for confidence level 1 up until confidence level 6, the number of “lesser known conditions” that individuals were familiar with tends to be very low, with the mean number of conditions known amongst all 6 confidence levels at only 2.155 lesser known conditions, as indicated by the data. As indicated by Figure 2, nearly 90% of respondents fell within the confidence levels 1-6. For comparative purposes, 30 conditions were listed in the survey. On the other hand, in the upper half of the distribution, a greater confidence generally indicated a greater likelihood of familiarity with more obscure conditions.
Figure 14

<table>
<thead>
<tr>
<th>Know Anyone</th>
<th>Advocate</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>71%</td>
</tr>
<tr>
<td>Unsure</td>
<td>74%</td>
</tr>
<tr>
<td>Yes</td>
<td>58%</td>
</tr>
<tr>
<td>Grand Total</td>
<td>62%</td>
</tr>
</tbody>
</table>

These data reveal cross-variable comparative trends between whether a respondent indicated that they knew someone with a Pediatric Neurological Condition and whether the same respondent was more likely to submit their name as an advocate for the brain mapping project.

A single-tailed z-test for two proportions was applied to compare the proportion of respondents willing to advocate for those with PNCs amongst both groups. This refers to both the group that did know someone with a PNC and the group that did not know anyone with a PNC. The proportion of individuals who were willing to advocate and also did not know anyone with a PNC was utilized for the null hypothesis ($p = 0.29$), while the proportion of individuals who were willing to advocate and did know someone with a PNC represented the alternative hypothesis ($p = 0.42$). The resulting $p$-value was 0.052. When compared to a standard benchmark of $\alpha = 0.1$, the result is statistically significant, indicating that there is a greater than 90% chance that the differing proportions of individuals willing to advocate amongst the aforementioned sub-groups is not due to chance. Respondents who knew individuals with Pediatric Neurological Conditions, empirically, were more willing to be listed as advocates for those with Pediatric Neurological Conditions.
Section IV: Conclusion

Individuals who knew someone with a PNC (a measure of exposure to information about PNC’s) were not only more confident about their knowledge of PNC’s but also more willing to advocate for those with Pediatric Neurological Conditions, empirically.

However, we find that of the 90% of respondents who fall within the 1-6 confidence level category, many are unaware of the scope of Pediatric Neurological Conditions as a whole. Several individuals who are relatively confident about their knowledge of PNC’s may not recognize the actual vastness of PNC’s. The fact that many relatively “confident” potential advocates may only be aware of a handful of more common conditions, such as Autism Spectrum Disorder, or Epilepsy, may lead to neglect in various spheres of life for individuals with little-known conditions simply because potential advocates aren’t aware of these conditions or their debilitating effects.

Insofar as it has been empirically demonstrated that younger individuals in the general populace are capable of changing information about PNC’s to an increased willingness to advocate, the issue of minimal advocacy can likely be remedied by even more information about the scope and effects of all Pediatric Neurological Conditions on those individuals afflicted by them, on their quality of life, and on their families.
Section V: Appendix

Appendix A: Survey Text

Survey Text: https://goo.gl/Xu2e8h
Please visit the link for a look at the survey given out to each respondent.

Appendix B: Raw Data

Raw Data: https://goo.gl/5VD95M
Please visit the link for a look at the raw data collected from the google survey used. This google sheet, is the data as received by the survey with little to no changes. For privacy reasons the names and emails of the respondents were removed.
Appendix C: Survey Flyer

WHAT:
The NeuroSurvey is an initiative to assess knowledge, consciousness, and awareness of neurological disorders, and in doing so, assist organizations and individuals in becoming better advocates on a local, state, and national level.

WHO:
CNS Foundation is collaborating with two Basking Ridge, NJ students, Davis George and Nikhil Kapadia. CNS Foundation is a nonprofit organization that facilitates research on the developing brain, provides information and resources to impacted families, and works with other patient advocates to raise public awareness about the importance of pediatric neurological research to expedite discovery of treatments and cures.

WHY:
The information provided is critical to assist organizations and individuals working to benefit pediatric neurological conditions to take action and increase public funding for treatments and cures. The dissemination of accurate and useful information regarding neurological disorders can act as a stepping stone to raise awareness, advance the scientific field, and make treatments and cures a reality.

FACTS ABOUT US:
• There are over 600 conditions that affect the pediatric brain. While Autism, Cerebral Palsy, and Traumatic Brain Injury are some of the most well-known, there is a large population suffering from rare or undiagnosed conditions.

• Of these 600 disorders, the causes of more than 90 percent are unknown. For the majority, there are no cures.

• In the United States alone, there are over 14 million children that suffer from pediatric neurological conditions. The numbers increase dramatically when taking into consideration the number of children worldwide that also have these conditions.

• The United States spends over half a trillion dollars annually on health care expenses and lost productivity relating to neurological disorders.

• Neurological research has historically focused on symptoms, prevention, and early intervention, while efforts to initiate brain repair have received little funding or attention.

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Act Now and find the survey at:
http://cnsfoundation.org/blog/neurosurvey
Section VI: References


