THE BLOG

High Rates of Autism Found in Federal Vaccine Injury Program: Study Says More Answers Needed

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By David Kirby

On Tuesday in Washington, members of the Elizabeth Birt Center for Autism Law and Advocacy (EBCALA), along with parents and children who received federal vaccine injury compensation, are having a press conference "to unveil an investigation linking vaccine injury to autism."

For the past two decades, according to the group, "the federal government has publicly denied a vaccine-autism link, while at the same time its Vaccine Injury Compensation Program (VICP) has been awarding damages for vaccine injury to children with brain damage, seizures and autism."

Their investigation, "based on public, verifiable government data, breaks new ground in the controversial vaccine-autism debate," and reports that "a substantial number of children compensated for vaccine injury also have autism — the evidence suggests that autism is at least three times more prevalent among vaccine-injured children than among children in the general population."

The following is a written Q&A conducted with EBCALA Directors:

Q) What is the Elizabeth Birt center, and who are the principal investigators on this project?

A) The Elizabeth Birt Center for Autism Law and Advocacy (EBCALA) is a nonprofit organization founded in 2008 to educate lawyers, advocates and parents about the legal challenges of autism (www.ebcala.org). The authors of this study are EBCALA board members. Mary Holland, Robert Krakow and Lisa Colin are attorneys and Louis Conte is a law enforcement officer who served as lead investigator.

Q) What were the main findings of this investigation?

A) The investigation found 83 cases of autism associated with compensated cases of vaccine-induced brain injury. It found that autism is at least three times more prevalent among vaccine injured children than among children in the general U.S. population today.

Q) How were the data compiled and analyzed?

We began collecting data over two years ago. We asked the federal government to provide us with this data through a Freedom Of Information Act request. We were told that our request would take four to five years, would cost \$750,000, and would afford us incomplete information. We then assembled data about VICP decisions from legal databases and settlement information from publicly available docket reports. We found 21 published cases detailing autism spectrum disorders by name or description, which the study includes. We then interviewed families that we located through the docket reports. We trained interviewers to use a structured interview form for gathering information about the compensated cases. We also asked parents to complete standardized screening questionnaires for autism and to provide additional documentation. In these interviews, 62 families reported autism associated with vaccine injury.

Q) What evidence do you have that all these children actually received an ASD diagnosis?

A) In almost half the 83 cases, we have confirmation of autism beyond parental report, including medical and education records and completed standard autism screening questionnaires which are have a high degree of accuracy. The study calls for the complete medical review of all compensated cases of vaccine injury, including formal autism diagnosis, where appropriate.

Q) The government has conceded that vaccine injury can lead to brain disease (encephalopathy) and seizure disorders, but what scientific evidence is there to show that these injuries can result in autism symptoms?

A) This study is a review of decided and settled cases of vaccine-induced brain injury; it does not purport to be a scientific study. HHS or the Vaccine Injury Compensation Program compensated these cases based on the best available scientific information. Through interviewing the families of compensated claims, we have uncovered an association between vaccine-induced brain injury and autism. The article suggests that there is significant overlap between the definition of autism and the VICP's definitions of encephalopathy, seizure and sequela (resulting events).

Q) Don't these results simply suggest that children with ASD are more susceptible to vaccine injury than typical children? In others words, wasn't the injury an effect, rather than a cause of the ASD?

A) The parents interviewed in this study report that vaccines caused their children's autism as well as brain damage and seizures. The study notes a clear association between vaccine injury and autism in 83 compensated cases. The government has not previously brought this association to public attention. Whether this association between vaccine injury and autism is causal is one of the critical unanswered questions to which the study seeks answers. That is why the study calls on Congress to investigate further and to require full medical and scientific evaluation of all compensated claims of vaccine injury.

Q) Many critics say that it is easy to win a case in the VICP ("Vaccine Court") and that the legal standards of proof are much lower than in civil court. Dr. Paul Offit called it a "Kangaroo Court" after Hannah Poling won compensation for her autism and epilepsy (though he praised the court when it ruled against children with autism) — what is your response?

A) The VICP and HHS rely on the best science available in making compensation decisions. Proceedings are based largely on scientific and medical evidence in a field that the Court of Appeals for the Federal Circuit has described as "bereft of complete and direct proof of how vaccines affect the human body." Less than one in five claims in the VICP have received compensation. There is little question that those cases that have received compensation, including the 83 noted in our study, were the result of vaccine injury. Yet despite having received compensation, most of the families we interviewed were highly critical of the VICP, finding it to be exceptionally slow, parsimonious and hostile to petitioners.

Q) Critics also charge that these are merely legal decisions made by administrative judges, and not scientific conclusions based on rigorous analysis of all the existing data, and as such, they have no bearing on the debate about the causes of autism. Your reply?

A) We disagree. These compensation decisions are based on the best medical and scientific information available to the VICP and HHS. Many peer-reviewed scientific studies have used these compensated cases to elucidate the nature of vaccine injury. We have uncovered an association between vaccine injury and autism. Because we were only able to reach a fraction of the more than 2,500 individuals compensated for vaccine injury, we believe that we have identified the tip of the iceberg of this association. The study calls on Congress to investigate further and to ensure rigorous scientific analysis of all cases of compensated vaccine injury.

Q) Others contend that most of the seizure disorders reported in your paper were compensated following DTP vaccination, and that the government removed seizure disorders as an outcome of the DTP vaccine years ago after new evidence showed there was no association.

They contend that these cases should not have been compensated and do not provide evidence of an association between vaccines and autism, especially since many ASD children also suffer from seizure disorders. Your response?

A) Residual seizure disorder was removed as a presumption for vaccine injury from the VICP; that certainly does not mean that vaccines no longer cause seizure disorders in some children. In practice, the removal has meant that compensation for vaccine-induced seizure disorder is more difficult, but there have many compensated cases since that removal nonetheless. The study details compensation decisions before and after the removal of residual seizure disorder as a presumption for causation.

Q) How many of the cases you listed were for DTP vaccine, and what other vaccines were involved?

A) Diphtheria-petussis-tetanus (DPT) is the stated cause for 62 of the 83 cases; measles-mumps-rubella (MMR) makes up the next largest group, followed by cases caused by the diphtheria-acellular pertussis-tetanus (DpaT) vaccine.

Q) Many people will dismiss this paper as the act of desperate parents who willfully ignore all of the epidemiological studies done to date that show no link between vaccines and autism. Do they have a point? Again, why should anyone care about the legal proceedings of some obscure court when so much published science says otherwise?

A) Government officials in HHS or the VICP decided that the children in this study suffered vaccine injury based on science. We uncovered that these children also have autism. How can the government then continue to assert that there is no link between vaccines and autism? If in fact there is no link, why would there be even one case of vaccine-associated autism, let alone 83? The government itself is now calling for more research on vaccines and autism, including the VICP itself. Congress should investigate the vaccine-autism association in the VICP.

Q) In addition to being legal professionals and EBCALA board members, the authors are parents of children with an ASD diagnosis, and two of them have claims before the VICP. Does this bias the reporting and analysis of the study?

A) The two authors' pending claims on behalf of family members are disclosed; those claims are not the subject of this study in any way. The authors' experiences fuel their motivation in undertaking this investigation; they do not bias the study results which are based exclusively on government compensation decisions and structured interviews conducted by trained researchers. No attorney-authors conducted interviews with parents or caregivers; only trained non-lawyer researchers conducted interviews to avoid any possible conflict of interest.

Q) Where and when will this paper be published?

A) The article will be published on Tuesday, May 10 in the Pace Environmental Law Review at digitalcommons.pace.edu.

Q) What impact do you hope it will have?

The article calls on Congress to investigate the Vaccine Injury Compensation Program and to ensure that there is a medical review of all compensated cases of vaccine injury. We hope that the article leads to these results.

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