

# Reprinted for Survivors of Reye's Syndrome

*Eight years ago, in our Fall 2000 In The News, we ran a Post Reye's Syndrome Study Report. Because we are receiving so many calls from Survivors who have questions we are reprinting the information.*

## Post-Reye's Syndrome Study Report

*A Project of the National Reye's Syndrome Foundation*

*Reported by Dr. Thomas Glick, M.D.,  
Scientific Board Chairman*

Everyone concerned with Reye's Syndrome had been concerned also about the problems that surviving children have had through their childhood and on into adult life. To the best of our knowledge, the neurological limitations and disabilities are mainly the results of secondary complications – especially the consequences of severe brain edema with pressure on vital structures – rather than from the primary disorders of metabolism, such as dysfunction of the liver.

This survey was not able to determine whether Reye's Syndrome survivors have had any unique neurological problems, but we think that this is somewhat unlikely. What does concern all of us is the pattern of problems that the survivors and their families have been experiencing, and the survey results have provided some information on this.

577 surveys were returned on 350 survivors (multiple family members were sent surveys). Of the 577 responses, 335 were completed by a parent or guardian. 143 from another family member, and 99 from a friend, although in some of these instances the survivor contributed in a large or small way to the information provided.

History prior to Reye's Syndrome: 97% were considered to have normal development, but not necessarily implying perfect health, 14% had some medical illness, 4.2% had a neurological or mental

illness, 3.3% reported a reaction to a chemical agent.

The occurrence of Reye's Syndrome in the patient: 90% had a prior 'viral' illness, and medication to reduce fever was used in 88%. There had been an immunization in the prior 30 days in only 2%.

With respect to Stage; 2% came to the hospital in Stage 0; Chemical Abnormalities only. 35% came to the hospital in Stage 1; Vomiting, etc. 33% in Stage 2; Confused, Combative, etc. 12% in Stage 3; Hyperventilation, etc. 13% came to hospital in Stage 4; Full Coma.

As the illness developed, 6.3% never progressed past Stage 1. 13% reached Stage 2, almost 10% reached Stage 3, and 66% reached stage 4, which shows this group of survivors had severe illness and that survivors with mild illness probably are underrepresented in the survey responses.

The diagnosis was made at the time of hospital admission in 48% of these survivors, but only subsequently during the hospital course in 46%, and only in retrospect, after discharge of 2.7%, or during recovery in a small minority of 3.3%.

### Residual Effects

The kinds of residual effects experienced by the survivors included impaired motor skills, 25%, impaired memory for new information, 21%, learning disability, 21%, speech and language disorder, 18%, behavioral disturbance memory for old information, 8.6%, and mental health problems (other than depression), 16.2%, as well as substance abuse, 3.6%. Several other effects were reported in very small percentages.

Of these survivors, 59% experienced at least one residual effect, and 50% currently still experience at least one effect. The average number of residual effects is 4.23 and 50% of survivors with any effects has at least 4 effects reported. Approximately 24% still experience 1-3 effects, and 25% experience 4 or more

effects. There is quite a wide variation in the number of effects present, as 10% of survivors had only 1 effect, 7.6% had 2 effects, 6.8% had 3 effects, 5.1% had 4 effects, and 4.5% each for 5 and 6 residual effects, beyond which the percentages are very small, down to the one person with 15 effects.

### Comment

Despite various limitations of this survey and its analysis, we can see that the survivors reported here were generally healthy until the illness, had mostly severe cases of Reye's Syndrome, were often not diagnosed early, and a majority had subsequent residual neurological problems. While some had motor impairments or seizures, most of those affected had more complex problems including memory, learning, behavior, and mental illness.

While such problems may not stand out to the casual observer as much as paralysis, for example, the families, friends, and many of the survivors themselves know how challenging such problems can be. Enormous patience and effort in rehabilitation has been required and is a credit to all concerned.

The National Reye's Syndrome Foundation appreciates the work of all who contributed to this survey and is proud of the efforts of survivors and their families to overcome the residual effects of this illness.

We hope all Reye's Syndrome Survivors can benefit from this information.

