Publique-se Inclua-se em pauta por cinco sessões
21/agosto/1995
RICARDO TRÍPOLI - Presidente

FLS. N.o 0
PROC. 7619

PROJETO DE LEI Nº 597, DE 1.995

Declara Utilidade Pública a Entidade que especifica.

A Assembléia Legislativa do Estado de São Paulo declara:

Artigo 1º - É declarada de Utilidade Pública a Associação Brasileira de Síndrome de Rett de São Paulo- Abre-te São Paulo, com sede em São Paulo SP.

Artigo 2º - Esta Lei entrará em vigor na data de sua publicação.

ENTREGUE À MESA EM: 17 AGO 1995 03355

PROTOCOLO
REGISTRO GERAL LEGISL.
7619 de 24/8/1995
Anuado c/ 94 fôlhas
Ass.

JUSTIFICATIVA

A Associação Brasileira de Síndrome de Rett de São Paulo: Abre-te São Paulo é uma Associação civil de direito privado, sem fins lucrativos, onde é vedado qualquer envolvimento em movimentos políticos, religiosos, ideológicos e raciais.

A Abre-te São Paulo tem sede e foro na cidade de São Paulo, à rua Dr. José Carlos de Toledo Piza, 215, ap. 161.

A Associação tem como objetivo congregar os esforços das famílias, profissionais, especialistas, técnicos e simpatizantes que desejam colaborar para :

a) coletar e divulgar informações precisas e objetivas que digam respeito a causa, diagnóstico, tratamento, prognóstico, prevenção e cura da Sindrome de Rett.

b) Reunir e dar apoio aos pais e/ou responsáveis de pacientes portadores da Síndrome de Rett.

c) Promover o entendimento e consciência da existência da Síndrome de Rett.

d) Incentivar o estudo, pesquisa, terapia e cura da Síndrome de Rett.

Considerando o relevante trabalho que é realizado pela Associação e reconhecendo a importância das atividades que desenvolve, contamos com a aprovação da presente propositura.

Sala das Sessões, em

DEPUTADA BEATRIZ PARDI

Divisão de Ordenamento Legislativo
Esta proposição contém
assinaturas
SDC, 21/8/1995

Chefe de Seção

597

ABRE-TE

Associação Brasileira de Síndrome de Rett de São Paulo

Abre-te

A Síndrome de Rett é uma desordem neurológica, que tem ocorrido somente em crianças do sexo feminino, entre a faixa etária do 6º até o 18º mês de vida, causando convulsões, escoliose, perda das funções das mãos, com movimentos estereotipados constantes, etc... É normalmente confundida com o autismo, paralisia cerebral e outras anomalias genéticas.

Com o objetivo de ajudar médicos e terapeutas a identificar seus portadores, características, estágios, etc...

Com o objetivo de ajudar os pais,...

Foi fundada a:

ABRE-TE - Associação Brasileira de Síndrome de Rett de São Paulo
Rua Dr. José Carlos de Toledo Piza, nº 215 - apto 161
Edifício Isabelle - Morumbi
Fones: 843.6073 - 965-12-65 - 491-78-78 - 703-01-76
CEP- 070-05712 - SÃO PAULO-SP

serving cake and coffee, Paula introduced her guests to IRSA and Rett syndrome. She also sent a catalog to past coworkers who mailed in their orders. Paula's daughter, Paula Rose, has RS.

Greg and Claudia Tupancy, Michigan Regional Representatives, sponsored a Tupperware event in which they sent out catalogs to friends who then sent in orders. This might make a good fund raiser for area gatherings, where each parent willing to do so takes a few catalogs home to pass on to friends. There was no actual party, just catalog distribution. Greg and Claudia's daughter, Katie, has RS.

For information on the Tupperware fundraising policies, contact your local dealer listed in your phone book.

A delightful surprise donation was received at the IRSA office from a group of students and the Inter-Community School in Zurich, Switzerland. These generous young people reached far outside of their own community in order to contribute toward the work at IRSA. What an inspiration to us all!

Susan Foster held a Phantom Tea recently to support IRSA. She sent a letter family and friends with a tea bag enclosed. On a special day at whatever time they could manage, they were invited to "Be with us in Spirit." This Phantom Tea, "You never had to attend" was held Sunday the 15th of November. A copy of the charming poem that accompanies the tea bag is available through the IRSA office, 9121 Piscataway Road, Suite 2B, Clinton, MD 20735. Please help by enclosing a self-addressed, stamped envelope.

Steve and Alice Anderson put together a five minute video about RS, including home videos of their daughter, Amanda, for a a United Way presentation to Steve's fellow employees at Pacific Gas and Electric Power Plant in Concord, California. Approximately 400 people attended. Many employees designated their contributions to be given to IRSA after the presentation. The Power Plant also held a separate fund raiser that raised funds for United Way, and through a unanimous vote designated all those funds to IRSA. Steve was then asked to give his presentation to another Power Plant and still more money was raised and designated to IRSA.

After hearing about Steve's success, his sister, Judy Angel decided to tell her fellow workers about IRSA in September. Judy was also successful in having many of her coworkers donate to IRSA through United Way.

If you would like to make a similar presentation, contact your IRSA office for further information. Each fall issue of the IRSA newsletter contains the United Way and Combined Federal Campaign donation information. For Combined Federal Campaign, designate agency number 0528. For donation through the United Way, encourage coworkers to fill out a donor option card, writing in the name of IRSA. Give some thought to presenting information about Rett syndrome to your coworkers, whether on a one-on-one basis, or through a presentation such as mentioned above. Every little bit helps!

Our newly established fund raising committee, chaired by Pete Hummert of Grover, Missouri, is just getting off the ground. At this writing, Pete is arranging to distribute canisters for change to be set on the counters of merchants in his area. Anyone interested in trying this in his or her own state, give Pete a call. Do remember to check into your state regulations for such canisters. If you have any fund raising ideas you would like to share, or if you have an interest in being on the fund raising committee please contact Pete at 16238 Marina Del Ray Lane, Grover, MO 63040, (314) 458-0253.

Brazilian families with Kathy Hunter at youth hostel in August 1992.

Brazil RSA Meeting

Kathy and Scott Hunter were guests of the Brazil Rett Syndrome Association at their very first conference held in Rio de Janeiro, August 15-16. Over 100 parents and professionals gathered to hear the latest information about RS. Kathy spoke to the group about believing in our girls and their ability to understand more than we have thought possible. Other topics on diagnosis, medical aspects, and care and management were well covered. More than anything, this meeting made it possible for many families who lived in isolated areas to know that they are not alone. Isis Riechelmann, founder of the association, had arranged for a donated bus to pick up families, and 45 family members shared the 18-hour ride to Rio. During the weekend, the families lived dormitory-style in a youth hostel. It was a very touching experience to see families connect in such a powerful way.

Most came from very poor areas with little resources for their daughters. In Brazil, education is not mandated for handicapped persons and most families cannot afford school and therapies. Gathered around the kitchen at the youth hostel, Kathy answered questions as parents strained to hear the translation in Portugese.

Most had brought picture albums with the story of their daughter's life etched on each page. Each wanted to know how they could help their daughter. As the time grew near for the bus to depart, many parents were overcome with emotion. One by one, they stood up to read aloud their expressions of hope and gratitude.

After a very inspirational weekend together, families piled back on the bus at 11 p.m. for the long, all-night ride home. It was hard to imagine the enormous challenges they all faced when they returned to their poor hometowns, but this time together gave them knowledge and strength—two ingredients very necessary for change. Their daughters will find a better tomorrow from what they learned and shared.

[illegible] Art. 177
[illegible] IX [illegible] Publique-se este
Despacho.
16 / março / 1999
[illegible] Presidente

Divisão de [illegible] Legislativo
Serviço de Processo Legislativo
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