Becoming a Culturally Competent Medical Home

A Model for Providing Patient- and Family-Centered Care to Children with Seizure Disorders”

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DAO

“Project Access”

To improve services for children ages 0 – 21 of Caribbean-Hispanic, Chinese and Caribbean non-Hispanic descent, diagnosed with epilepsy. To increase the number of consistent and culturally competent medical homes for children with epilepsy and their families.

Project Goals

To improve co-management and communication between parents, primary care providers, and specialists by facilitating meetings between parents and providers as necessary.

To collaborate with parent partners and community partners to create care partnership support tools such as: care plans; seizure action plans; and epilepsy notebooks.

To educate primary care providers and sub-specialist about the diverse cultural needs of families of children & youth with epilepsy.

Key Process Measures

- Increase by 50% the number of children with epilepsy written medication list
- Increase by 50% the number of children with epilepsy who have a care plan/seizure action
- Increase by 50 % the number of children with epilepsy who are linked with a Primary Care Provider (PCP)/Medical Home (MH)

Six components to improve community-based system of services for children and youth with epilepsy and/or seizure disorders

1. Partnerships between professionals and families of children and youth with epilepsy
2. Access to a culturally competent family-centered medical home which coordinates care to pediatric subspecialties.
3. Access to adequate health insurance and financing of services.
4. Early and continuous screening for epilepsy and seizure disorders.
5. Organized community services for easy use by families.
6. Transition to adult health care.

Local Level Learning Collaborative

EFMNY Education Department

- Community Health Centers
- Community Health Fairs
- Public & Private Schools
- Hospitals
- Epilepsy Workshops
- Parent Groups
- Community-Based Organizations
- New York City Department of Health
- New York State Department of Health
- New York city Board of Education
- Title V Website
- Pre-Schools/Head Starts
- EFMNY Website

EFMNY MSC Department

- Families
- Community Health Centers
- Clinicians
- Schools
- Community-Based Organizations
- Home Health Aide Agencies

Project Access II
New York Team

Parents

- Parent-to-Parent
- Pediatricians (Medical Home)
- Specialists
- Other professional care providers such as day camp, respite, etc.
- Clinicians
- School Nurses

Project Partners

- Families/Patients
- School Nurses
- Other health care providers
- Care Coordinators
- Clinicians
- Medical Students

1. Partnerships between professionals and families of children & youth with epilepsy

- Enhanced the Learning Collaborative by recruiting new members such as pediatrician, specialists, school nurses, and parents.

- Engaged community providers such as specialists and specialty nurse practitioners in community epilepsy education.

- Involved parents to review all new materials and current materials to ensure proper cultural competency and epilepsy education for other parents

- Parent partners served as advisors to project staff on best practices.

One of the biggest challenges that we encountered was related to identifying the second site (Chinese community).

PCPs/sub-specialists interviews summary (N=28)

- PCPs reported to have varying levels of knowledge regarding epilepsy and seizure disorders in children and are largely unfamiliar with current treatment modalities

- All PCPs interviewed felt that their practices always or usually provided a medical home, and were confident that their practices provided care coordination for their patients in accordance with the definition provided

- Both primary care physicians and sub-specialists agreed that their staff, their patients', and the patients' families would benefit from additional professional epilepsy trainings and materials as well as access to non-medical epilepsy related resources such as service coordination, socialization programs, vocational services, and supported employment programs

PCPs/sub-specialists interviews summary, Cont.

- Reimbursement from Medicaid and other insurance providers can often be viewed as insufficient, and a barrier to providing appropriate primary and specialty care for children
- The availability of support groups for children and youth with epilepsy was only somewhat able to meet the need
- All in all, insurance was a source of major frustration to parents, and likely limited access to care and the choices that patients were able to make regarding their care
- Parents were frustrated by the lack of coordination of care their children receive, and deem the communication between primary care physicians and specialists as inadequate

Medical Home Self-Assessment Results

All Sites Comparison (N=20)										
Background Questions	**Level 1**		**Level 2**		**Level 3**		**Level 4**		**Blank**	**Total**
Knowledge of MH concept	1		7		10		0		2	20
Knowledge of Family centered care	4		6		7		1		2	20
I. Organizational Capacity	**Level 1**		**Level 2**		**Level 3**		**Level 4**		**Blank**	0
	Partial	**Complete**	**Partial**	**Complete**	**Partial**	**Complete**	**Partial**	**Complete**		0
Walker Providers	0	11	9	13	15	6	0	1	1	56
Walker SW & Nursing	0	5	4	18	14	8	3	4		56
Flushing Providers	2	2	2	4	5	10	2	1		28
II. Chronic Condition Management	**Level 1**		**Level 2**		**Level 3**		**Level 4**		**Blank**	0
	Partial	**Complete**	**Partial**	**Complete**	**Partial**	**Complete**	**Partial**	**Complete**		0
Walker Providers	0	5	11	25	7	0	0	0		48
Walker SW & Nursing	1	2	5	8	10	5	10	5	2	48
Flushing Providers	0	1	2	6	3	6	0	0	6	24
III. Care Coordination	**Level 1**		**Level 2**		**Level 3**		**Level 4**		**Blank**	0
	Partial	**Complete**	**Partial**	**Complete**	**Partial**	**Complete**	**Partial**	**Complete**		0
Walker Providers	3	11	14	7	7	2	1	0	3	48
Walker SW & Nursing	2	1	7	3	16	11	7	1		48
Flushing Providers	0	2	1	1	4	9	0	0	7	24

Medical Home Self-Assessment Results

IV. Community Outreach	Level 1		Level 2		Level 3		Level 4		Blank	0
	Partial	Complete	Partial	Complete	Partial	Complete	Partial	Complete		0
Walker Providers	3	5	4	2	2	0	0	0		16
Walker SW & Nursing	2	1	2	2	5	1	3	0		16
Flushing Providers	0	1	0	0	1	4	0	0	2	8
V. Data Management	Level 1		Level 2		Level 3		Level 4		Blank	0
	Partial	Complete	Partial	Complete	Partial	Complete	Partial	Complete		0
Walker Providers	0	0	1	0	5	3	5	2		16
Walker SW & Nursing	0	0	0	0	1	2	5	8		16
Flushing Providers	0	0	0	0	1	3	1	1	2	8
VI. Quality Improvement/ Change	Level 1		Level 2		Level 3		Level 4		Blank	0
	Partial	Complete	Partial	Complete	Partial	Complete	Partial	Complete		0
Walker Providers	4	2	0	2	4	2	0	0	2	16
Walker SW & Nursing	0	0	1	0	7	5	3	0		16
Flushing Providers	0	0	0	0	4	2	0	0	2	8

Charts Review Results

Partner site (N=12)		
	Yes	**No**
# of Children with a *specialist*	2	10
# of children taking *antiepileptic drugs*	11	1
# of children with a *seizure action plan*	0	12
# of children with a *epilepsy care plan*	0	12
# of children with a *home medication list*	11	1
# of youth with a *health care transition plan (pediatric care to adult care*	0	12
# of children with a *medical home*	12	

2. Access to a culturally competent family-centered medical home

1. Identified a pediatrician/nurses as champions to test the medical home model at their practices.
2. Educated providers about the medical home concept & why they should do it.
3. Educated parents about the medical home concept and why their child should have one.
4. Participated in local and national medical home policy initiatives to raise awareness (HRSA and NICHQ).
5. Utilized the Medical Home tools developed by the National Center for Medical Home Implementation for the partner practices.
6. Educated parents about the medical home concept.
7. Reached out to AAP and other local medical home initiatives for advice and guidance.
8. Conducted mini sessions to educate providers and parents about the medical home concept and improvement model.

Parents Focus Group

In a 2008 focus group for parents of children and youth with epilepsy , parents expressed concerns about their child’s doctor’s attitude toward their cultural background and the lack of interest in knowing how to communicate with families from different cultures.

The group of 10 new immigrant parents from different parts of Latin America preferred taking their child to the emergency room, than to their regular doctor with whom they did not successfully establish good communication.

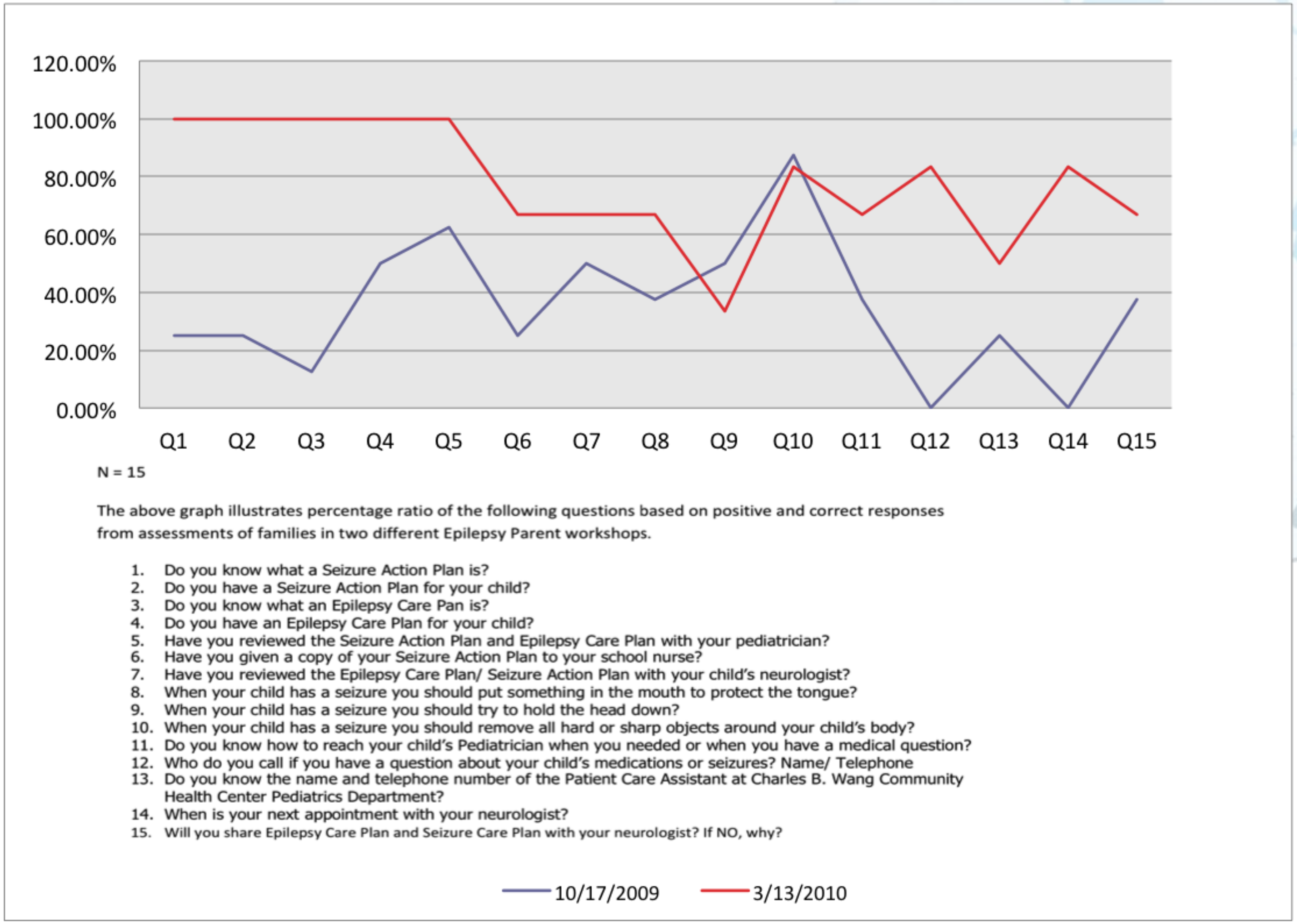
Focus Group Lessons Learned

- Parents needed help learning how to advocate for their children in a school setting; this was a potential area for parent-to-parent partnerships
- Some parents felt like THEY were the main health care provider for their child
- Getting an appointment with a specialist was a lengthy process for some parents, but for others it happened within days
- Communication between doctors was likely to occur when the doctors were within the same health system but less likely to occur between doctors in different health care systems
- Language barriers lead to miscommunication; translation services although available, were used often

Focus Groups Lessons Learned, Cont.

- Parents who actively sought out information and asked questions felt satisfied with the information received regarding their child's health condition
- Some patients felt like they were the expert on their child's medications, while other's preferred to defer to the doctor
- All parents agreed that there was a need to research and inform themselves about child's medications
- The importance of clear information about treatments in their native language was essential

Epilepsy Parent Workshop Survey Comparison Site



N = 15

The above graph illustrates percentage ratio of the following questions based on positive and correct responses from assessments of families in two different Epilepsy Parent workshops.

1. Do you know what a Seizure Action Plan is?
2. Do you have a Seizure Action Plan for your child?
3. Do you know what an Epilepsy Care Pan is?
4. Do you have an Epilepsy Care Plan for your child?
5. Have you reviewed the Seizure Action Plan and Epilepsy Care Plan with your pediatrician?
6. Have you given a copy of your Seizure Action Plan to your school nurse?
7. Have you reviewed the Epilepsy Care Plan/ Seizure Action Plan with your child's neurologist?
8. When your child has a seizure you should put something in the mouth to protect the tongue?
9. When your child has a seizure you should try to hold the head down?
10. When your child has a seizure you should remove all hard or sharp objects around your child's body?
11. Do you know how to reach your child's Pediatrician when you needed or when you have a medical question?
12. Who do you call if you have a question about your child's medications or seizures? Name/ Telephone
13. Do you know the name and telephone number of the Patient Care Assistant at Charles B. Wang Community Health Center Pediatrics Department?
14. When is your next appointment with your neurologist?
15. Will you share Epilepsy Care Plan and Seizure Care Plan with your neurologist? If NO, why?

Epilepsy Parent Workshop Survey Comparison Site

Summary:
The assessment reflected a high inclined in family knowledge of epilepsy tools from below 20% to above 60% in questions 1 thru 7. However, these data revealed a slight instability towards topics related to seizure care and first aid from questions 8 thru 10, from close to 30% increase in question 8 and a drop in questions 9 and 10. This became the focus future parent support workshops.

Communication and interaction between families, primary care physicians, and neurologist improved through the usage of the Care Book and assistance of Medical Home Initiative, which is shown from questions 11 thru 15. There is an up to 80% improvement in communication between families and health care providers. Overall, these evaluations demonstrated significant progress towards achieving better health care for children with epilepsy.

3. Access to adequate health insurance and financing of services

Organization linked project to its internal resources:

- Utilized the education department resources to impart epilepsy workshops and distributed materials to parents and providers.
- Linked families their children to intensive follow-up or additional referrals such as case management, crisis intervention, and clinical services.

Project staff worked with parents to make sure children had adequate access to health insurance in order to obtain appropriate services.

3. Access to adequate health insurance and financing of services, Cont.

- An internal and external referral systems was developed
- Face to face assessment with were done to find out the type of service (s) parents needed
- Internal referrals were sent to the correct department for service and follow up
- If external referrals, the care coordinator contacted the agency directly for follow-up
- 153 families were successfully referred for crisis intervention, case management, or clinical services.
- 225 epilepsy workshops were completed by the organization education department

4. Early and continuous screening for epilepsy and seizure disorders

- Offered culturally competent epilepsy education for parents at head star programs
- Provided in person education or literature at pediatric clinics in order for parents to have the information about epilepsy
- Worked with early intervention programs to disseminate education materials to parents
- Worked with the New York City Department of Health-Division of Children with Special Needs to develop a resource system

Objectives were evaluated as follow:

- Scheduled at least 1 head start presentation a month, targeting the Hispanic and Chinese communities
- Provided epilepsy information in Spanish and Chinese to agencies working with these populations.

5. Organized community services for easy use by families

- Develop a bilingual resource guide for families and organizations
- Established a Memorandum of Agreement with community-based organizations and health care clinics in order exchange and share information about patient’s services
- Engaged pilot sites to promote not only health care services but also community resources such as early intervention programs, social services, and education information to families of children with epilepsy

Objectives were evaluated as follow:

- Identified about 50 different community-based organizations serving the Hispanic and American Chinese communities in the Bronx, Manhattan, Queens, and Brooklyn

6. Transition to adult health care

- Developed a health care assessment plan
- Translated health care transition assessment in Chinese and Spanish
- Tested tool with 20 youth
- Distributed health care transition to schools and clinics
- Made tool accessible to youth and parents

Objective were evaluated as follow:

- Tested the English version with 26 families
- Made revisions based on comments and feedback

Cultural Competence Medical Home (CCMH)®

1. Culturally Accessible
1. Linguistic Comprehensive (verbally, written, visual, body language)
1. Culturally Competent Resources Coordinated
1. Culturally Educational
1. Family-centered
1. Continuous Holistic Approach
1. Compassionate

Cultural Competence Medical Home (CCMH)®

- Patient with chronic health conditions come from many different cultural backgrounds
- Helping patients understand and accept the medical home concept
- Ensure that patient's cultural differences are understood and addressed according to their individual needs
- Patient's cultural beliefs come first before any medical facts or statistics
- Cultural competence and diversity must be one of the top priorities when implementing patient-centered medical home

Cultural Competence Medical Home (CCMH)®, Cont.

CARIBBEAN – HISPANIC	ASIAN – CHINESE	CARIBBEAN – NON – HISPANIC
Know the differences in cultures within the Hispanic/Latino community. (Dominican Republic, Cuba, and Puerto Rico).	Know the differences in cultures within the Chinese community.	We started working with this community in year 3 and were able to distribute the care book. The care book was not translated in any other language; so far the English has met the families needs.
Learn about the stigma that epilepsy has within specific Latino communities (In general, the Latino community has very similar beliefs such as "contagious", "possession of evil spirits", only children get it", etc.	Learn about the stigma that epilepsy has within the Chinese community such as "contagious", "possession of evil spirits", only children get it", "people have mental problems", "mental retardation", etc.	Learn about the stigma that epilepsy has within the Caribbean communities such as "contagious", "possession of evil spirits", only children get it", etc.
Learn the name given to epilepsy by different groups; such as "fit", "el patatus", "la chiripiolca", "esta loco", etc. however, educate community about the clinical name so they can become aware of it in order to communicate more effectively with providers.	In the Chinese cultural, there are many different dialects; In New York City the two main languages spoken are Mandarin and Cantonese, two different languages. However, the written Chinese language is "universal" but still with some differences. For instance; Tradition Chinese is mainly used in the United States.	A health care professional, health educator, or someone who brings knowledge into the community is perceived as a subject authority/expert. However, trust must be built in order to have any effect in delivering the information and acquiring the desired change in attitude or behavior of the community.

Cultural brokers help families/providers bridge the cultural divide

Why Cultural Brokering? Community attitudes about epilepsy

- According to a community-based survey conducted by EFMNY in 2007 and 2008, about 40% of Hispanic adults stated that they believed that epilepsy was contagious and that their parents and grandparents had told them not to approach or touch someone having a “fit” because they would “catch it.” Hispanic adults also expressed the belief that someone having a “convulsion” was possessed by an “evil spirit.”

- The results showed that about 90% of parents were not satisfied with their children’s specialty care or care provided by specialists. Parents expressed a number of concerns about their doctors including lack of cultural sensitivity, inability to “connect” with them, and lack of communication.

Cultural brokers help families/providers bridge the cultural divide

Why Cultural Brokering? Community attitudes about epilepsy

- Lack of knowledge among physicians about the cultures and language of the populations served - According to information gained from interviews, the doctors treating children and youth with epilepsy and their families were not sure about how to deal with what they perceived as families' resistance to epilepsy treatment and services.

- The doctors noted that even though they used interpreters when serving families with limited English proficiency, the families seemed to be missing important information about their children's care.

- The doctors were unable to connect with the families because they were not effectively learning about and addressing the families' values and beliefs about epilepsy and its treatment.

Cultural brokers help families/providers bridge the cultural divide

Cultural brokering has been defined as a health care intervention through which the professional increasingly uses cultural and health science knowledge and skills to negotiate with the client and the health care system for an effective, beneficial health care plan (Wenger, 1995).

A cultural broker can serve as a liaison, cultural guide, and mediator among patients, their families, and health care providers and organizations. A cultural broker can also serve as a catalyst for change to assist health care providers and organizations in adapting policies and practices to the cultural contexts of patient populations and communities served.

Cultural broker interventions outcomes

- Some of the pilot sites, started to train residents about cultural and linguistic competence
- Cultural issues became an important consideration to address during case conferences
- Better communication between families and providers
- Families became more confortable at sharing information and more willing to talk honestly about what they were doing in caring for their children
- Providers improved their openness to receive information about family approaches to caring for their children that may differ from their medical recommendations
- One of the most important outcomes was better partnerships between providers and families to create shared solutions to issues of care for children with epilepsy.

Cultural broker interventions outcomes, Cont.

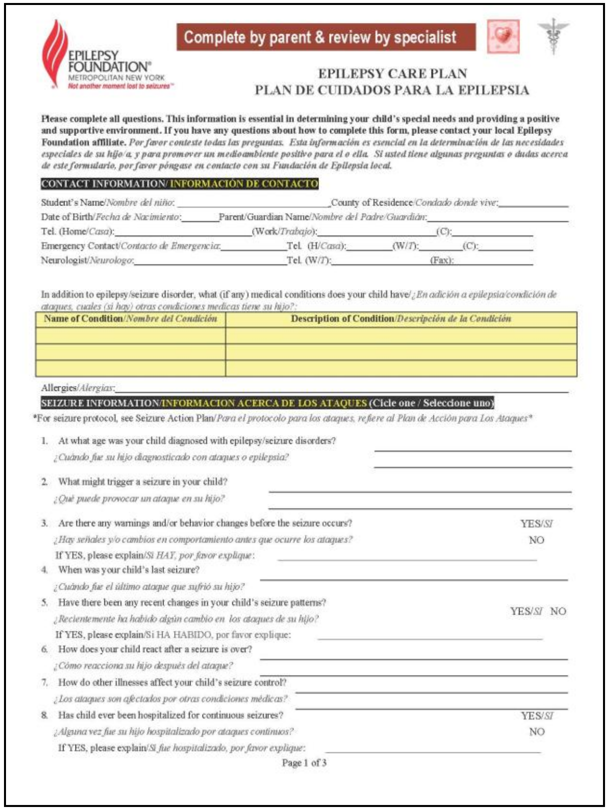
- Cultural brokering was sustained at some of the pilot sites
- One pilot site funded the care coordinator, who continues to work as a cultural broker for families seeking specialty care
- In the past, attempts to provide support groups for families were not successful, but with the relationships and trust built by the cultural broker, one of the sites was able to offer this service for families.

A high-Level Performing Practice Can…

- Communicate in cross-cultural context
- Provide services 2 or more languages
- Access to interpret and/or translation services
- Advocate with & on behalf of patients & their families
- Negotiate health, mental health & other service delivery system
- Communicate well with patients
- Treat patients with respect, listen to them, give them information and keep communication lines open
- Insure for accurate communication of information in languages other than English.

Caribbean-Hispanic/ Asian-Chinese
Tools/Products Developed

Care Plan *(Bilingual: Spanish/English)*



Complete by parent & review by specialist

EPILEPSY FOUNDATION®
METROPOLITAN NEW YORK
Not another moment lost to seizures™

EPILEPSY CARE PLAN
PLAN DE CUIDADOS PARA LA EPILEPSIA

Please complete all questions. This information is essential in determining your child's special needs and providing a positive and supportive environment. If you have any questions about how to complete this form, please contact your local Epilepsy Foundation affiliate. *Por favor conteste todas las preguntas. Esta información es esencial en la determinación de las necesidades especiales de su hijo/a, y para promover un medioambiente positivo para el o ella. Si usted tiene algunas preguntas o dudas acerca de este formulario, por favor póngase en contacto con su Fundación de Epilepsia local.*

CONTACT INFORMATION/ INFORMACIÓN DE CONTACTO

Student's Name/*Nombre del niño*: ______________________, County of Residence/*Condado donde vive*: ____________
Date of Birth/*Fecha de Nacimiento*: ______ Parent/Guardian Name/*Nombre del Padre/Guardián*: ____________________
Tel. (Home/*Casa*): ____________________ (Work/*Trabajo*): ____________________ (C): ____________
Emergency Contact/*Contacto de Emergencia*: __________ Tel. (H/*Casa*): ________ (W/*T*): ________ (C): __________
Neurologist/*Neurologo*: ____________________ Tel. (W/*T*): ____________________ (Fax): ____________

In addition to epilepsy/seizure disorder, what (if any) medical conditions does your child have/*¿En adición a epilepsia/condición de ataques, cuales (si hay) otras condiciones medicas tiene su hijo?*:

Name of Condition/*Nombre del Condición*	**Description of Condition**/*Descripción de la Condición*

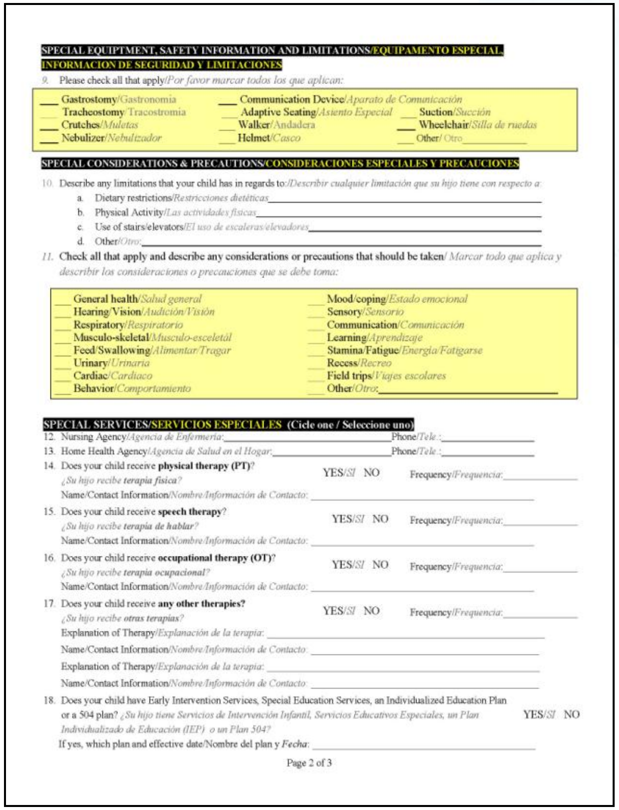
Allergies/*Alergias*: ____

SEIZURE INFORMATION/INFORMACION ACERCA DE LOS ATAQUES (Cicle one / Seleccione uno)

*For seizure protocol, see Seizure Action Plan/*Para el protocolo para los ataques, refiere al Plan de Acción para Los Ataques**

1. At what age was your child diagnosed with epilepsy/seizure disorders? ____________
   ¿Cuándo fue su hijo diagnosticado con ataques o epilepsia? ____________
2. What might trigger a seizure in your child? ____________
   ¿Qué puede provocar un ataque en su hijo? ____________
3. Are there any warnings and/or behavior changes before the seizure occurs? YES/*SI*
   ¿Hay señales y/o cambios en comportamiento antes que ocurre los ataques? NO
   If YES, please explain/*Si HAY, por favor explique*: ____________
4. When was your child's last seizure? ____________
   ¿Cuándo fue el último ataque que sufrió su hijo?
5. Have there been any recent changes in your child's seizure patterns? YES/*SI* NO
   ¿Recientemente ha habido algún cambio en los ataques de su hijo?
   If YES, please explain/Si HA HABIDO, por favor explique: ____________
6. How does your child react after a seizure is over? ____________
   ¿Cómo reacciona su hijo después del ataque? ____________
7. How do other illnesses affect your child's seizure control? ____________
   ¿Los ataques son afectados por otras condiciones médicas? ____________
8. Has child ever been hospitalized for continuous seizures? YES/*SI*
   ¿Alguna vez fue su hijo hospitalizado por ataques continuos? NO
   If YES, please explain/*Si fue hospitalizado, por favor explique*: ____________

Page 1 of 3



SPECIAL EQUIPTMENT, SAFETY INFORMATION AND LIMITATIONS/EQUIPAMENTO ESPECIAL, INFORMACION DE SEGURIDAD Y LIMITACIONES

9. Please check all that apply/*Por favor marcar todos los que aplican:*

___ Gastrostomy/Gastronomia
___ Tracheostomy/ Tracostromia
___ Crutches/*Muletas*
___ Nebulizer/*Nebulizador*
___ Communication Device/*Aparato de Comunicación*
___ Adaptive Seating/*Asiento Especial*
___ Walker/ Andadera
___ Helmet/*Casco*
___ Suction/*Succión*
___ Wheelchair/*Silla de ruedas*
___ Other/ Otro ____________

SPECIAL CONSIDERATIONS & PRECAUTIONS/CONSIDERACIONES ESPECIALES Y PRECAUCIONES

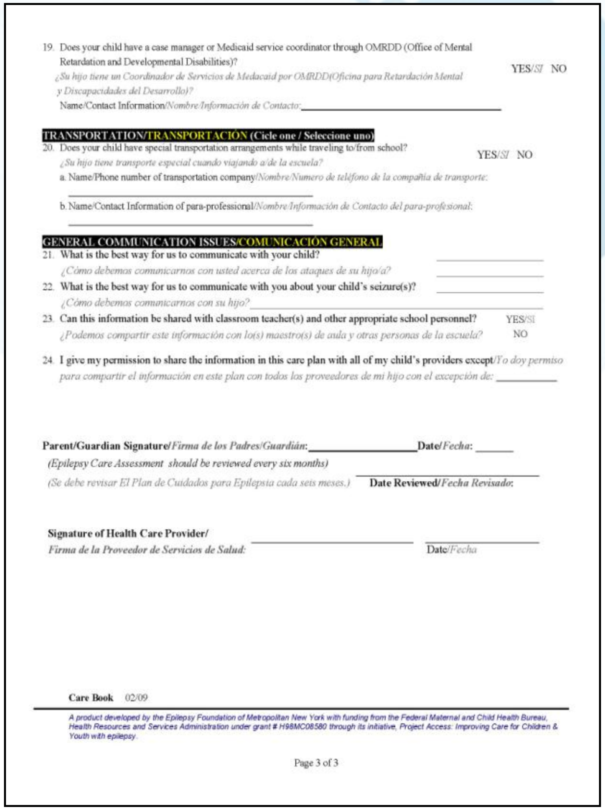
10. Describe any limitations that your child has in regards to:/*Describir cualquier limitación que su hijo tiene con respecto a:*
    a. Dietary restrictions/*Restricciones dietéticas* ____________
    b. Physical Activity/*Las actividades físicas* ____________
    c. Use of stairs/elevators/*El uso de escaleras/elevadores* ____________
    d. Other/*Otro*: ____________
11. **Check all that apply and describe any considerations or precautions that should be taken**/ *Marcar todo que aplica y describir los consideraciones o precauciones que se debe toma:*

___ General health/*Salud general*
___ Hearing/Vision/*Audición/Visión*
___ Respiratory/*Respiratorio*
___ Musculo-skeletal/*Musculo-esceletál*
___ Feed/Swallowing/*Alimentar/Tragar*
___ Urinary/*Urinaria*
___ Cardiac/*Cardiaco*
___ Behavior/*Comportamiento*
___ Mood/coping/*Estado emocional*
___ Sensory/*Sensorio*
___ Communication/*Comunicación*
___ Learning/*Aprendizaje*
___ Stamina/Fatigue/*Energía/Fatigarse*
___ Recess/*Recreo*
___ Field trips/*Viajes escolares*
___ Other/*Otro*: ____________

SPECIAL SERVICES/SERVICIOS ESPECIALES (Cicle one / Seleccione uno)

12. Nursing Agency/*Agencia de Enfermería*: ____________ Phone/*Tele.*: ____________
13. Home Health Agency/*Agencia de Salud en el Hogar*: ____________ Phone/*Tele.*: ____________
14. Does your child receive **physical therapy (PT)**? YES/*SI* NO Frequency/*Frequencia*: ________
    *¿Su hijo recibe **terapia fisica**?*
    Name/Contact Information/*Nombre/Información de Contacto*: ____________
15. Does your child receive **speech therapy**? YES/*SI* NO Frequency/*Frequencia*: ________
    *¿Su hijo recibe **terapia de hablar**?*
    Name/Contact Information/*Nombre/Información de Contacto*: ____________
16. Does your child receive **occupational therapy (OT)**? YES/*SI* NO Frequency/*Frequencia*: ________
    *¿Su hijo recibe **terapia ocupacional**?*
    Name/Contact Information/*Nombre/Información de Contacto*: ____________
17. Does your child receive **any other therapies?** YES/*SI* NO Frequency/*Frequencia*: ________
    *¿Su hijo recibe **otras terapias**?*
    Explanation of Therapy/*Explanación de la terapia*: ____________
    Name/Contact Information/*Nombre/Información de Contacto*: ____________
    Explanation of Therapy/*Explanación de la terapia*: ____________
    Name/Contact Information/*Nombre/Información de Contacto*: ____________
18. Does your child have Early Intervention Services, Special Education Services, an Individualized Education Plan or a 504 plan? *¿Su hijo tiene Servicios de Intervención Infantil, Servicios Educativos Especiales, un Plan Individualizado de Educación (IEP) o un Plan 504?* YES/*SI* NO
    If yes, which plan and effective date/Nombre del plan y *Fecha*: ____________

Page 2 of 3



19. Does your child have a case manager or Medicaid service coordinator through OMRDD (Office of Mental Retardation and Developmental Disabilities)? YES/*SI* NO
    ¿Su hijo tiene un Coordinador de Servicios de Medacaid por OMRDD(Oficina para Retardación Mental y Discapacidades del Desarrollo)?
    Name/Contact Information/*Nombre/Información de Contacto*: ____________

TRANSPORTATION/TRANSPORTACIÓN (Cicle one / Seleccione uno)

20. Does your child have special transportation arrangements while traveling to/from school? YES/*SI* NO
    ¿Su hijo tiene transporte especial cuando viajando a/de la escuela?
    a. Name/Phone number of transportation company/*Nombre/Numero de teléfono de la compañía de transporte*: ____________
    b. Name/Contact Information of para-professional/*Nombre/Información de Contacto del para-profesional*: ____________

GENERAL COMMUNICATION ISSUES/COMUNICACIÓN GENERAL

21. **What is the best way for us to communicate with your child?** ____________
    ¿Cómo debemos comunicarnos con usted acerca de los ataques de su hijo/a? ____________
22. **What is the best way for us to communicate with you about your child's seizure(s)?** ____________
    ¿Cómo debemos comunicarnos con su hijo? ____________
23. **Can this information be shared with classroom teacher(s) and other appropriate school personnel?** YES/SI
    ¿Podemos compartir este información con lo(s) maestro(s) de aula y otras personas de la escuela? NO
24. **I give my permission to share the information in this care plan with all of my child's providers except**/*Yo doy permiso para compartir el información en este plan con todos los proveedores de mi hijo con el excepción de:* ________

Parent/Guardian Signature/*Firma de los Padres/Guardián*: ____________ **Date/*Fecha*:** ______
(Epilepsy Care Assessment should be reviewed every six months)
(Se debe revisar El Plan de Cuidados para Epilepsia cada seis meses.) ____________ **Date Reviewed/*Fecha Revisado*:**

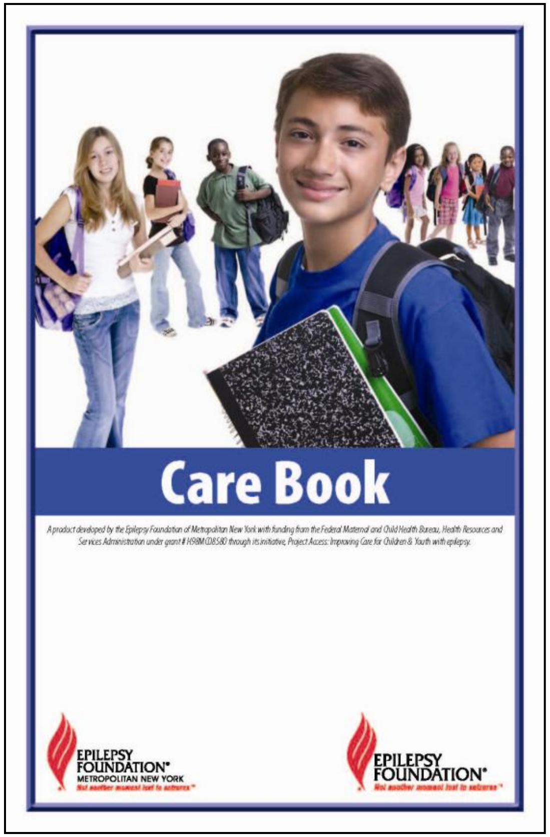
Signature of Health Care Provider/
***Firma de la Proveedor de Servicios de Salud*:** ____________ ____________ Date/*Fecha*

Care Book 02/09

A product developed by the Epilepsy Foundation of Metropolitan New York with funding from the Federal Maternal and Child Health Bureau, Health Resources and Services Administration under grant # H98MC08580 through its initiative, Project Access: Improving Care for Children & Youth with epilepsy.

Page 3 of 3

Caribbean-Hispanic/ Asian-Chinese
Tools/Products Developed, Cont.



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The Epilepsy Foundation of Metropolitan New York

Since 1967 thousands of people with epilepsy and their families have received information or have benefited from the comprehensive social and educational services offered by the Epilepsy Foundation of Metropolitan New York (formerly known as The Epilepsy Institute). Staffed with professionals from the medical, social work, vocational counseling and psychological professions, the six metropolitan New York Epilepsy Foundation of Metropolitan New York offices and sites - in Manhattan, the Bronx, Queens, Brooklyn and Westchester County - provide a wide variety of services to persons with epilepsy, their families and the community. The Epilepsy Foundation of Metropolitan New York, a non-profit agency, is certified by New York State and maintains contractual agreements with New York City, New York State, and Westchester County.

La Fundació para la Epilepsia del área Metropolitana de Nueva York

Desde 1967 miles de personas con epilepsia y sus familias han recibido información o se han beneficiado de los servicios sociales y educativos ofrecidos por la fundación para la epilepsia del área metropolitana de Nueva York (conocida antes como El Instituto para la Epilepsia). Proveído con los profesionales del campo trabajo médico, social, del asesoramiento vocacional y de las profesiones psicológicas, la Fundación para la Epilepsia del área metropolitana Nueva York tiene seis oficinas en el área metropolitana de Nueva York - en Manhattan, el Bronx, Queens, Brooklyn, y el condado de Westchester - proporcione una variedad amplia de servicios a las personas con epilepsia, a sus familias y a la comunidad. La Fundación para la Epilepsia del área metropolitana de Nueva York, es una agencia sin usos lucrativos, es certificada por el estado de Nueva York y mantiene acuerdos contractuales con New York City, el estado de Nueva York, y el condado de Westchester.

Project Access: Improving Care for Children and Youth with Epilepsy

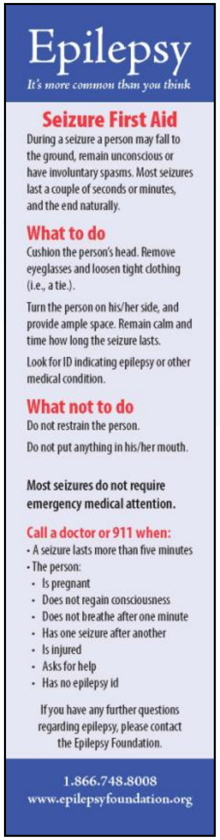
The Epilepsy Foundation of Metropolitan New York in partnership with the National Epilepsy Foundation of America is honored to be a grantee for this project. Please visit out website at www.efmny.org for more information on Project Access.

La Fundación para la Epilepsia del área Metropolitana de Nueva York en colaboración con la Fundación para la Epilepsia de América tiene el honor de ser uno de los recipientes del Project Acceso. Para mas información por favor visite www.efmny.org.

Information to be completed by Parent/Guardian

Information to be review or completed by specialist

Tel. 212.677.8550 Fax 212.677.5825 www.efmny.org



Epilepsy
It's more common than you think

Seizure First Aid

During a seizure a person may fall to the ground, remain unconscious or have involuntary spasms. Most seizures last a couple of seconds or minutes, and the end naturally.

What to do

Cushion the person's head. Remove eyeglasses and loosen tight clothing (i.e., a tie.).

Turn the person on his/her side, and provide ample space. Remain calm and time how long the seizure lasts.

Look for ID indicating epilepsy or other medical condition.

What not to do

Do not restrain the person.

Do not put anything in his/her mouth.

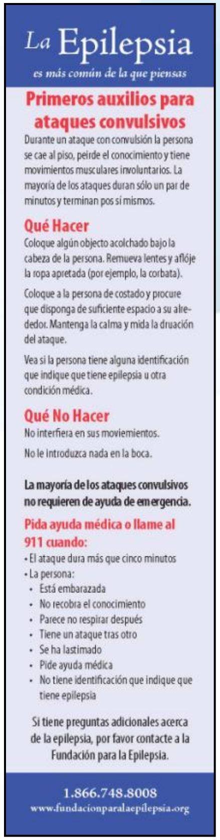
Most seizures do not require emergency medical attention.

Call a doctor or 911 when:

- A seizure lasts more than five minutes
- The person:
  - Is pregnant
  - Does not regain consciousness
  - Does not breathe after one minute
  - Has one seizure after another
  - Is injured
  - Asks for help
  - Has no epilepsy id

If you have any further questions regarding epilepsy, please contact the Epilepsy Foundation.

1.866.748.8008
www.epilepsyfoundation.org



La Epilepsia
es más común de la que piensas

Primeros auxilios para ataques convulsivos

Durante un ataque con convulsión la persona se cae al piso, peirde el conocimiento y tiene movimientos musculares involuntarios. La mayoría de los ataques duran sólo un par de minutos y terminan pos sí mismos.

Qué Hacer

Coloque algún objecto acolchado bajo la cabeza de la persona. Remueva lentes y aflóje la ropa apretada (por ejemplo, la corbata).

Coloque a la persona de costado y procure que disponga de suficiente espacio a su alrededor. Mantenga la calma y mida la druación del ataque.

Vea si la persona tiene alguna identificación que indique que tiene epilepsia u otra condición médica.

Qué No Hacer

No interfiera en sus moviemientos.

No le introduzca nada en la boca.

La mayoría de los ataques convulsivos no requieren de ayuda de emergencia.

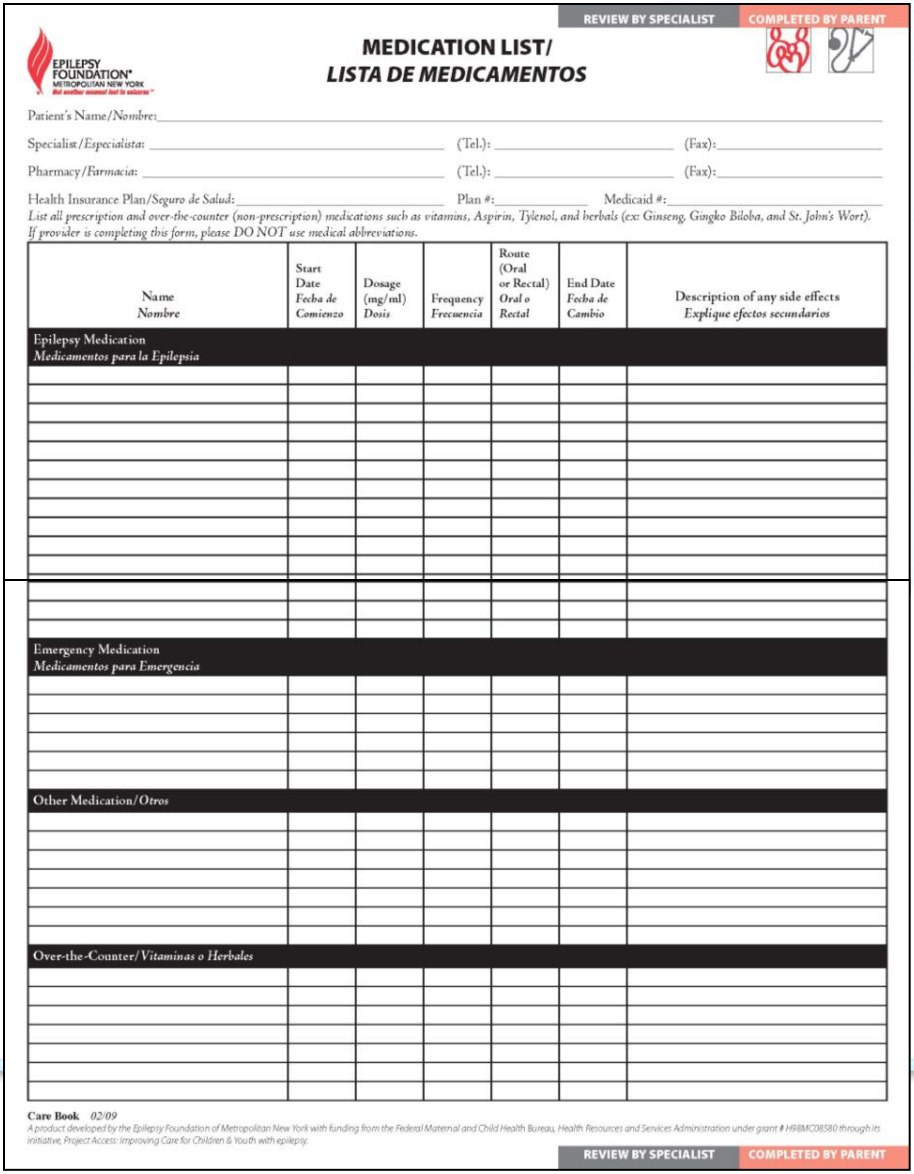
Pida ayuda médica o llame al 911 cuando:

- El ataque dura más que cinco minutos
- La persona:
  - Está embarazada
  - No recobra el conocimiento
  - Parece no respirar después
  - Tiene un ataque tras otro
  - Se ha lastimado
  - Pide ayuda médica
  - No tiene identificación que indique que tiene epilepsia

Si tiene preguntas adicionales acerca de la epilepsia, por favor contacte a la Fundación para la Epilepsia.

1.866.748.8008
www.fundacionparalaepilepsia.org

Caribbean-Hispanic/ Asian-Chinese
Tools/Products Developed, Cont.



REVIEW BY SPECIALIST | COMPLETED BY PARENT

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MEDICATION LIST/
LISTA DE MEDICAMENTOS

Patient's Name/*Nombre*: ____________________

Specialist/*Especialista*: ____________________ (Tel.): ____________________ (Fax): ____________________

Pharmacy/*Farmacia*: ____________________ (Tel.): ____________________ (Fax): ____________________

Health Insurance Plan/*Seguro de Salud*: ____________________ Plan #: ____________________ Medicaid #: ____________________

List all prescription and over-the-counter (non-prescription) medications such as vitamins, Aspirin, Tylenol, and herbals (ex: Ginseng, Gingko Biloba, and St. John's Wort). If provider is completing this form, please DO NOT use medical abbreviations.

Name *Nombre*	Start Date *Fecha de Comienzo*	Dosage (mg/ml) *Dosis*	Frequency *Frecuencia*	Route (Oral or Rectal) *Oral o Rectal*	End Date *Fecha de Cambio*	Description of any side effects *Explique efectos secundarios*
Epilepsy Medication *Medicamentos para la Epilepsia*						
Emergency Medication *Medicamentos para Emergencia*						
Other Medication/*Otros*						
Over-the-Counter/*Vitaminas o Herbales*						

Care Book *02/09*

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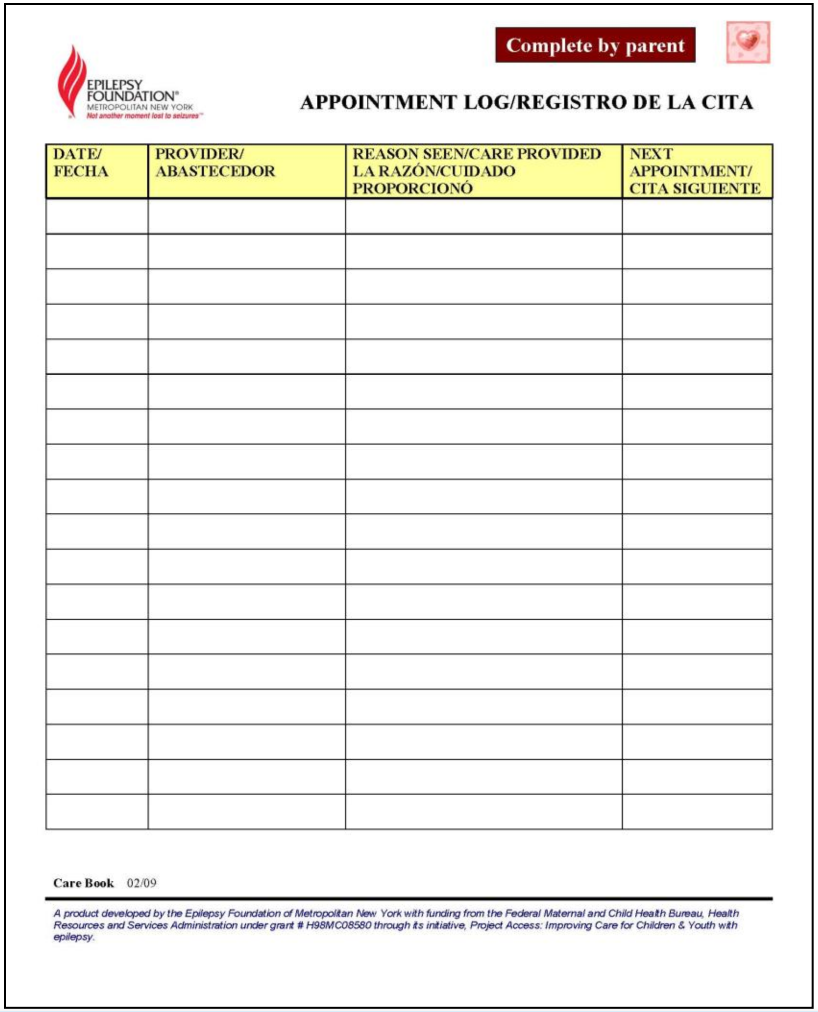
REVIEW BY SPECIALIST | COMPLETED BY PARENT

Caribbean-Hispanic/Asian-Chinese Tools/Products Developed, Cont.



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Complete by parent

APPOINTMENT LOG/REGISTRO DE LA CITA

DATE/ FECHA	PROVIDER/ ABASTECEDOR	REASON SEEN/CARE PROVIDED LA RAZÓN/CUIDADO PROPORCIONÓ	NEXT APPOINTMENT/ CITA SIGUIENTE

Care Book 02/09

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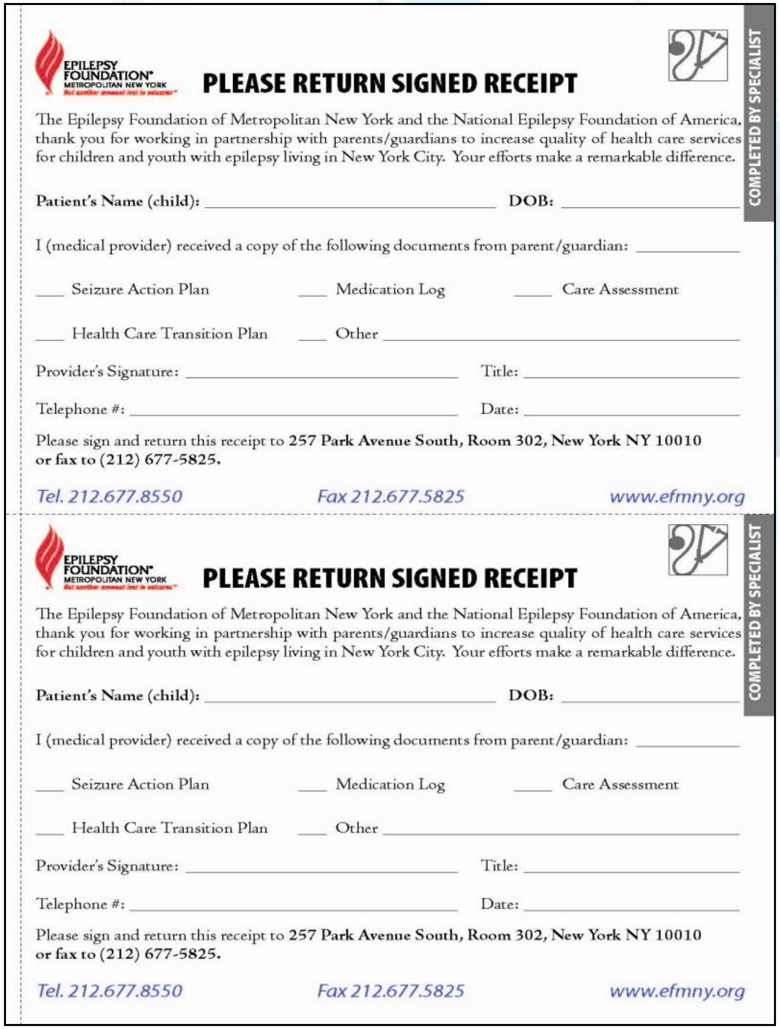

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PLEASE RETURN SIGNED RECEIPT

COMPLETED BY SPECIALIST

The Epilepsy Foundation of Metropolitan New York and the National Epilepsy Foundation of America, thank you for working in partnership with parents/guardians to increase quality of health care services for children and youth with epilepsy living in New York City. Your efforts make a remarkable difference.

Patient's Name (child): ____________________ **DOB:** ____________

I (medical provider) received a copy of the following documents from parent/guardian: ________

___ Seizure Action Plan ___ Medication Log ___ Care Assessment

___ Health Care Transition Plan ___ Other ____________________

Provider's Signature: ____________________ Title: ____________

Telephone #: ____________________ Date: ____________

Please sign and return this receipt to **257 Park Avenue South, Room 302, New York NY 10010 or fax to (212) 677-5825.**

Tel. 212.677.8550 *Fax 212.677.5825* *www.efmny.org*

EPILEPSY FOUNDATION®
METROPOLITAN NEW YORK

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Tel. 212.677.8550 Fax 212.677.5825 www.efmny.org

Tools tracking

1. External follow-up tracking

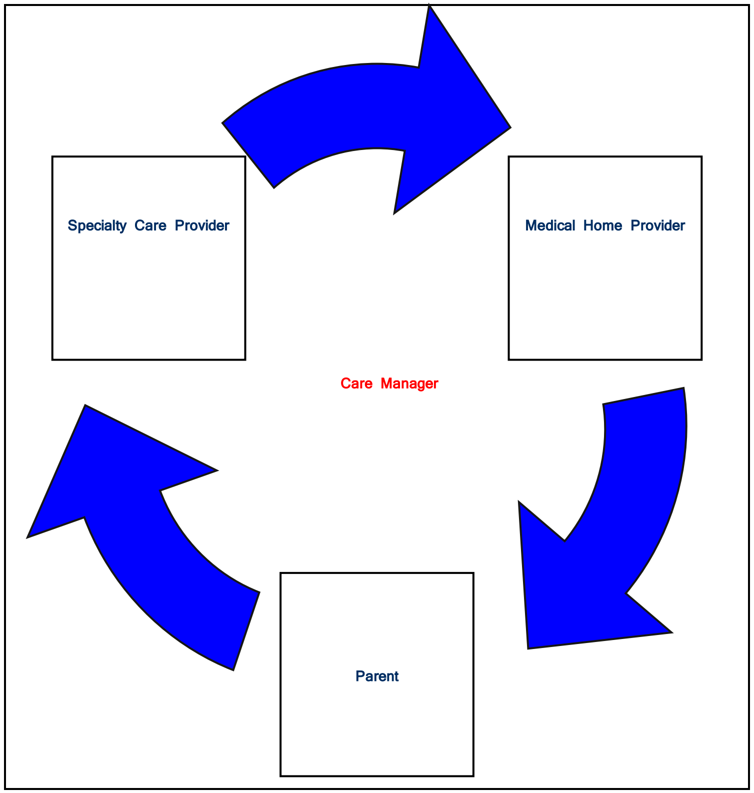
No.	Name (Parent)	Youth	Age	State-Services	Epilepsy ONLY	Home Address	Boro	State	Zip	Phone	Email	Nationality	Tool(s)	Transition Plan	Month

2. Internal follow-up tracking Medicaid Service Coordination Department

Location/Agency	Seizure Action Plan	Care Plan	Medication List	Transition Plan	Follow-up Timeline		
EFMNY MSC					Given to MSC 1/15/10	30 day follow-up (distribution)	60 day follow-up (plans completed by specialist)

Primary/specialist communication log

Primary/Specialist Circle of Communication

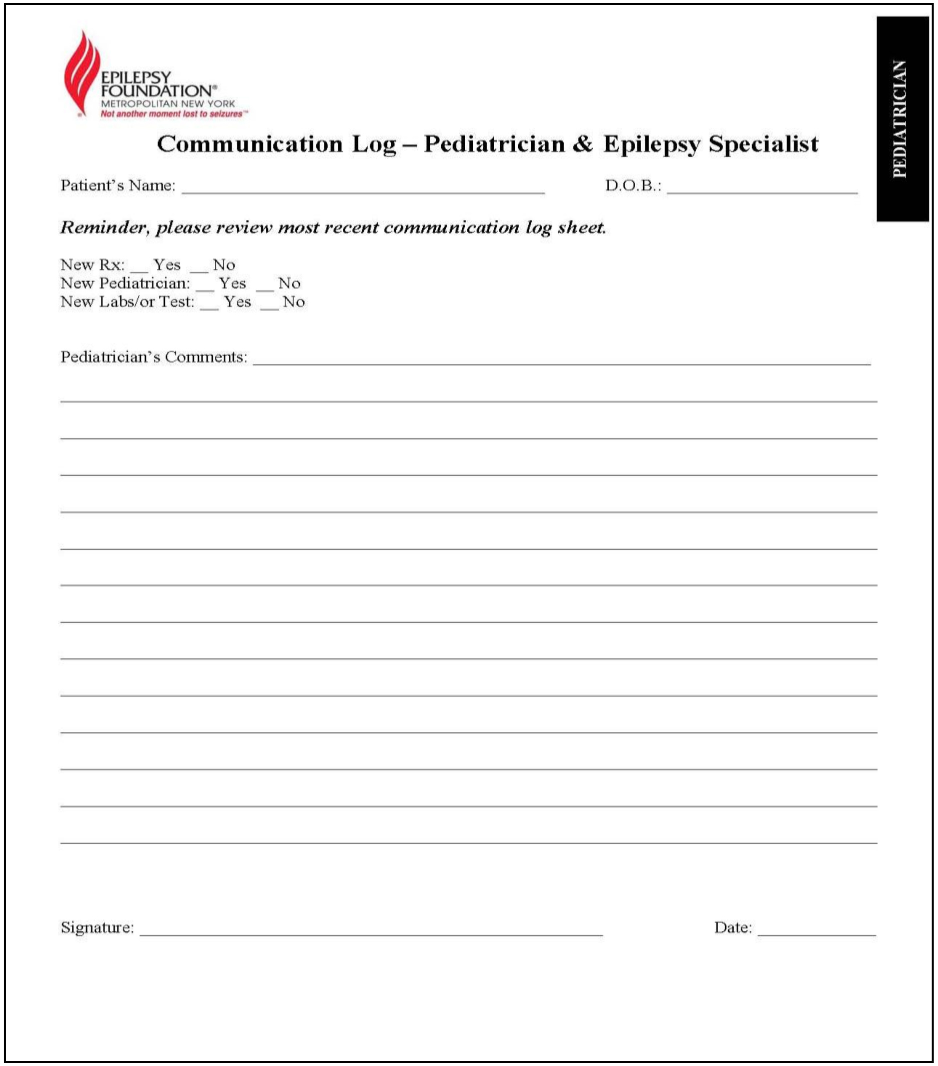


Specialty Care Provider

Medical Home Provider

Care Manager

Parent



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PEDIATRICIAN

Communication Log – Pediatrician & Epilepsy Specialist

Patient's Name: ______________________ D.O.B.: ____________

Reminder, please review most recent communication log sheet.

New Rx: __ Yes __ No
New Pediatrician: __ Yes __ No
New Labs/or Test: __ Yes __ No

Pediatrician's Comments: ____

Signature: ______________________________ Date: __________

Project accomplishments

1. Montefiore Hospital integrated the seizure action plan into their internal electronic medical records.
2. Through the EFMNY intervention, CBW and Beth Israel epilepsy clinic continued providing epilepsy education/training to their families and staff.
3. Partners continued with access to epilepsy resources for their families and staff through the partnership created with EFMNY (i.e., epilepsy literature)
4. Statewide distribution of seizure action plan was sustained through New York State Department of Health.
5. Cultural competence education for providers was sustained through links to online curriculums developed by the NCCC, the usage of bilingual tools, and the cultural competence & access to health care guide developed by EFMNY.
6. The cultural broker model was sustained through the continued presence of EFMNY staff at least to two partner sites.

Project accomplishments, Cont.

7. Conducted follow-up assessments on the medical home, tools usage and implementation by our partners. Example:
    - Quarterly follow-up assessment
    - Six months follow-up assessment
    - Annual follow-up assessment

8. Provided in person surveillance, to the work continued by partners as follow:
    - Continued visiting 3 out of 4 partners on a monthly basis to assess ongoing family educational workshops. In addition to monitor the seizure action plan, care plan, and note book implementation with new patients.

9. Developed and implemented a media campaign targeting Hispanic and the American Chinese communities

Project accomplishments, Cont.

- **Bilingual Care Book**
  - Provided parents training on care book usage
- **Bilingual Health Care Transition Plan**

  Bilingual – English/Spanish & English/Chinese)
  - Some partners implemented the care plan for children/youth with epilepsy, and was modified for other groups such as teens with autism
- **Bilingual Seizure Action Plan**
  - It was implemented at schools
- **Medical Home Initiative**
  - Provided assistance to a FQHC in initiating the medical home approach for children with epilepsy
  - 2 more New York City pediatric departments has requested our assistance with the medical home initiative.

Project accomplishments, Cont.

癲癇發作的急救常識

進行全身性僵直陣攣發作急救的須知:

- 保持鎮定、安撫患者附近的人
- 切勿嘗試制止患者的抽搐或動作
- 記錄患者發作的持續時間
- 把患者四周可造成危險的堅硬或尖銳的物品移走
- 鬆解患者的領帶或其他阻礙呼吸的衣物
- 在患者頭下平放軟墊或衣物，例如摺疊好的外套
- 將頭轉向一側，以保持呼吸道暢通
- 切勿強行把物件塞進患者口中，以免弄傷牙齒或顎骨。當發生抽搐時，患者不會吞下自己的舌頭。
- 陪伴病患至神智清醒為止。

何時應該叫救護車?

以下有幾種情況:

- 當癲癇發生在水中時
- 患者身上沒有病史識別卡或不清楚抽搐是否因癲癇發作所致
- 懷孕婦人、受傷或糖尿病人
- 連續抽搐發作超過五分鐘
- 多次發作而神智不清者
- 陣攣停止後仍無法恢復知覺

關於癲癇症的事實

- 全美有超過 3 百萬不同年齡的癲癇病患
- 10%的美國人會在一生中曾經歷一次癲癇發作
- 每年大約有二十萬個新病例，其中有70%病因不明
- 每年有四萬五千個十五歲以下的兒童會患上癲癇症
- 3%的人在七十五歲之前會患上癲癇症

Epilepsy Foundation of Metropolitan New York
紐約大都會癲癇基金會

257 Park Ave. South, # 302
New York, NY 10010
電話: 212-677-8550
傳真: 212-677-5825

網址: www.efmny.org
電子郵件: Chinese-ny@efmny.org

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服務華人社區

Project accomplishments, Cont.

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我們服務紐約市社區已超過四十年。如果您有任何有關癲癇病的問題，請聯繫紐約大都會癲癇基金會

電話 傳真
電子郵件 ______________ 網址

The Medical Home Model in a Culturally Diverse Community

Video

https://www.youtube.com/watch?v=JYP7r7g8QFE (short version)

http://vimeo.com/24466467 (Full version)

Patient/Family-Centered Medical Homes
Selected Primary Care Initiatives

- **Patient-Centered Primary Care Collaborative (PCPCC)**
  http://www.pcpcc.net
- **AAP National Center for Medical Home Implementation**
  http://www.medicalhomeinfo.org/
- **AAFP TransforMED**
  http://www.transformed.com
- **NCQA Patient-Centered Medical Home**
  http://www.ncqa.org/tabid/631/default.aspx
- **AAFP – Road to Recognition: Your Guide to NCQA Medical Home**
  http://www.aafp.org/online/en/home/membership/initiaties/pcmh/afpleads/aafppcmh/ncqaquide.html
- **PCPCC – Proof in Practice**
  http://pcpcc.net/files/PilotGuidePip.pdf

Video Resources

- **Think–Speak–Act Cultural Health: Part 1**https://www.thinkculturalhealth.hhs.gov/FlashPlayer/play508.asp?Video=QHpart1

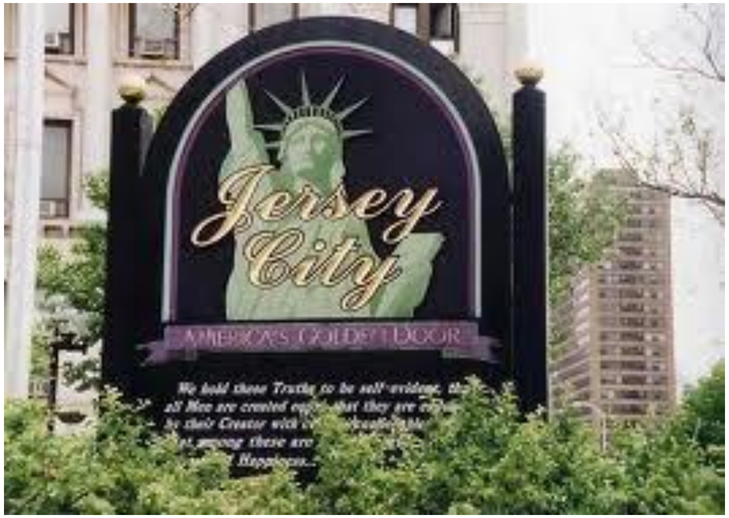
- **The Medical Home Model in a Culturally Diverse Community**
  Dao Management Consulting Services, Inc.

  http://vimeo.com/user7168375/medicalhomemodelculturallydiversecommunitycultural-broker

- **Medical Assistants: Addressing Language and Culture in Health Care Practices** Medical Leadership Council on Cultural Proficiency California Academy of Family Physicians and CAFP Foundation

  http://www.vimeo.com/15822032

Contact Information



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Email: helen@daoconsultingservices.com

National Center for Cultural Competence
Georgetown University Center for Child & Human

IMC USA
Institute of Management Consultants USA

DAO.