

November 14, 2012

In 2007, the State established the NJ Autism Registry in order to improve services for New Jersey children affected by Autism. This registry enables the State to plan and provide services to autistic children and their families. Health care providers are required to register any person under the age of 22 and a resident of NJ. At this time, your child is not registered and we would like your help in accomplishing this task. Registration will allow you to receive information about services available and you will be linked to the Case Management Unit in your county.

Please go to our website, touchpointpediatrics.com, click on the Autism Registry button and download the instructions, forms and brochure. Please complete the forms to the best of your ability and send them back to us within two weeks. We will then add any other information we have and forward it to the Autism Registry.

You *cannot refuse* to have your child registered but you can ask that personal identifying information such as name and address be withheld. If this is your choice, you need to send us back this signed letter (*see below*) indicating that request along with the completed registration. We will abide by your wishes and will only forward non-identifying data to the State. In that case, the State will not reach out to you with information about services nor link you to the Case Management Unit in your county.

If you have any questions, you can call the Registry at 609-292-5676. You can also call and speak with our nurse Pat.

Thank you for your cooperation in this matter. It is important to us that our patients receive all the assistance that is appropriate and available to them to manage the many issues associated with this diagnosis. Our goal is always to have our patients reach their maximum potential.

Sincerely,

Jennifer Shaw-Brachfeld, MD

Margot Kerrigan, MD

Valerie Tom, MD

Stuart Slavin, MD

Please withhold my child's name and address when including him/her in the Autism Registry.

Child's name:			
	Print Name	Date of Birth	Today's Date
Parent/Guardian:			
	Print Name	Sigi	nature

## SPECIAL CHILD HEALTH SERVICES REGISTRATION, Form SCH-0 INSTRUCTIONS AND LEGENDS

#### **INSTRUCTIONS**

#### **Registration Type**

- New first time a child is registered by hospital/reporting facility, also use when Registration type is unknown.
- Update updated information for a child previously known to be registered by hospital/reporting facility.
- Audit child found to be the result of an audit conducted by state Birth Defects Registry staff.

#### Type of Hospital/Reporting Facility

• Refer to legend below, choose the most appropriate.

#### **Case Tracking Information**

• Provide if available – used to identify updated registrations from same hospital/reporting facility or duplicate registrations from separate hospitals.

#### Name of Contact

 Individual from hospital/reporting facility who is to be contacted regarding any questions concerning the registration

 there should only be one person per hospital/reporting facility designated as the contact person.

#### **Child's Information**

• Use information as it appears on the Birth Certificate.

#### **Child's Current Residence**

- Should reflect the address where the child resides at the time of registration.
- If a child is living in a facility, then the facility's address is entered in this section.
- Unit description refer to legend below.

#### Hospital/Place of Birth

- If the birth took place in a New Jersey facility, then the name of the facility should be written in the space.
- If the birth took place in New Jersey, but not at a medical facility, then write "NJ non-medical facility" in the space.
- If the birth took place in NY, PA, DE, or MD, then refer to legend below for a list of selected hospitals that should be written in the space.
- If the birth took place in the United States, but not in New Jersey or at one of the selected hospitals listed in the legend below, then write "out-of-state" in the space and the city and state in which the birth occurred.
- If the birth was a "home" birth, then write "Home Birth" in the space and the city and state in which the birth took place.
- If the birth took place outside of the United States, then write "out-of-country" in the space and the name of the country.
- If the birth place is unknown, then write "unknown" in the space.

#### **Transfer Information**

- Provide information on only the most recent transfer.
- Only the hospital/facility name should be written into the space for "received from" and "sent to".
- In the case of a "home" birth, the child is considered a transfer and the "received from" space should reflect the manner in which the child was transported to the hospital, e.g., ambulance, private car, taxi, etc.

#### **Birth Information**

• Birth order should be a number only, e.g., 1, 2, rather than an alpha character (A,B).

### Primary Language Spoken in Home

Refer to legend below.

### Birth Mother's Residence at Time of Birth

- As the address appears in the Electronic Birth Certificate.
- If the birth mother was institutionalized at the time of birth, then the address immediately prior to institutionalization should be used, unless she became pregnant while institutionalized, in which case use the address of the institution.
- If the birth mother is homeless, then use the last known address.
- If the birth mother's residence at time of birth is unknown, then check unknown.

### **Parent A Information**

- If one parent is the birth mother, then Parent A Information should correspond to the birth mother.
- If neither parent is the birth mother, but one parent is a biological parent, then Parent A Information should correspond to the biological parent.
- If neither parent is a biological parent, then Parent A Information may correspond to either parent.
- Biological if the biological connection of the parent is known, then either the "yes" or "no" box should be checked; if the biological connection of the parent is unknown, then the "unknown" box should be checked.
- Maiden Name if applicable, complete, otherwise write "NA".
- Mailing Address the address used to send mail to the parent (should be the same as in the Electronic Birth Certificate); if the mailing address is the same as the child's current address, then check "same as child's current residence address" box.
- Legal Guardian Status reflects the parent's legal authority to act on behalf of the child; a biological parent is assumed to be the child's legal guardian unless a court has terminated guardianship; a non-biological parent's guardianship is assigned by the courts; if the guardian status is unknown, then check the "unknown" box.

#### **Parent B Information**

- Corresponds to the other parent.
- If unknown, then leave blank.
- Biological if the biological connection of the parent is known, then either the "yes" or "no" box should be checked; if the biological connection of the parent is unknown, then the "unknown" box should be checked.
- Mailing Address the address used to send mail to the parent (should be the same as in the Electronic Birth Certificate); if the mailing address is the same as the child's current address, then check "same as child's current residence address" box.
- Legal Guardian Status reflects the parent's legal authority to act on behalf of the child; a biological parent is assumed to be the child's legal guardian unless a court has terminated guardianship; a non-biological parent's guardianship is assigned by the courts; if the guardian status is unknown, then check the "unknown" box.

#### **Guardian Agency Information**

- Legal Guardian Status reflects the legal authority to act on behalf of the child and is assigned by the courts; if the guardian status is unknown, then check the "unknown" box.
- Guardian Type categorizes the guardian as either an agency (government or private) or an individual (relative or non-relative); if the child is placed with a Foster Parent, then the Guardian Type is "Individual (Non-Relative)"; a DYFS case must have signed documents denoting such.

- Guardian Agency Information corresponds to the government or private agency assigned guardianship of the child.
- Guardian Agency Contact Information corresponds to the individual at the government or private agency who should be contacted regarding any questions concerning the child.

#### **Guardian's Information**

• Corresponds to the individual (relative or non-relative) who is assigned guardianship of the child; only a single name should be entered, e.g., John Jones or Mary Jones, even though the guardians may be John Jones and Mary Jones.

#### **LEGENDS**

#### Type of Hospital/Reporting Facility

- Acute care hospital (ACH)
- Birthing center free standing not hospital based (BC)
- Case Management Unit (CMU)
- Clinical laboratory (CL)
- County government agency (DOH, etc.) (CGA)
- Day care/school (DCS)
- Early Intervention (EI)
- Home health agency (HHA)
- Long-term care hospital (LTCH)
- Medical/Dental practice (MDP)
- Medical examiner (ME)
- Municipal/City government agency (MCGA)
- Other professional practice (Audiologists, etc.) (ProP)
- Other
- Parents/relative (PR)
- Specialty center (SpecC)
- State government agency (DYFS, etc.) (SGA)

#### Selected Out-of-State Hospitals

<u>New York</u>

- Bellevue Hospital
- The Children's Hospital of New York Presbyterian
- Elmhurst Hospital Center
- Lenox Hill Hospital
- Lincoln Hospital
- Long Island College Hospital
- Long Island Jewish Hospital
- Montefiore Medical Center
- Mount Sinai Medical Center
- New York University Medical Center
- Sloan Kettering Hospital
- St. Anthony (Warwick)
- St. Clare's Hospital
- St. Luke's Medical Center
- Westchester Medical Center

#### Pennsylvania

- Abington Memorial Hospital
- Albert Einstein Medical Center
- Children's Hospital of Philadelphia (CHOP)
- Hahnemann Medical College
- Hospital of the University of Pennsylvania
- Pennsylvania Hospital
- St. Christopher's Hospital for Children
- Thomas Jefferson University
- Temple University Hospital
- Wills Eye Hospital

#### <u>Delaware</u>

- Al DuPont Hospital for Children
- Christiana Children's Hospital

#### Maryland

• Johns Hopkins Hospital

 Mailing Address – the address used to send mail to the guardian; if the mailing address is the same as the child's current address, then check "same as child's current residence address" box.

#### **Diagnosis Description**

- Diagnosis should reflect physician's diagnosis, as noted on the medical record.
- Do not use diagnosis from medical records sheet.
- Do not use diagnosis based on only ICD-9 CM code.

#### Unit Description (address)

- APT (Apartment)
- BSMT (Basement)
- DEPT (Department)
- FL (Floor)
- FRNT (Front)
- REAR (Rear)
- RM (Room)
- STE (Suite)
- UNIT (Unit)

#### Primary Language

- English
- Spanish
- American Sign Language
- Augmentative Communication
- Afghani
- African
- Arabic
- Cambodian
- Cantonese
- Chinese
- Farsi
- French
- French Creole
- German
- Hebrew
- Hindi
- Hmong
- Japanese
- Korean
- Laotian
- Mandarin
- Native American
- Pacific Islander
- Persian
- Polish
- Portuguese
- RussianScandinavian
- Tagalog
  Turkish

Vietnamese

Yiddish

Unknown

Other

#### Autism Supplemental Information (SCH-1) Form

- Required component for Autism reporting
- Information is specific to the diagnosis of autism

#### Non-identifiable Registration

- If parent/guardian requests a non-identifiable registration, then check this box.
- Applies to Autism only registrations congenital diagnoses registrations require all information on SCH-0 Form.
- Write pre-printed number from the SCH-0 Form (if using the pre-printed SCH-0) in place of the child's name.
- Report only month and year of birth.

#### **Registration Type**

- First registration first time a child is registered by diagnostician or diagnostician's practice when the diagnostician is a member of a group practice.
- Revised updated diagnosis information for a child previously registered by diagnostician.

#### Diagnosis

- Only one diagnosis may be selected.
- Autism Spectrum Disorders is a category heading and shall not be selected as a diagnosis.
- If Rett Syndrome selected, then indicate whether or not the diagnosis was confirmed by genetic tests.
- No longer meets criteria or Misdiagnosis previously registered but no longer meets criteria.

#### **Date of Diagnosis**

• Complete mmddyy date is preferred; however, at least month and year must be reported. This reflects the date of service which prompted this registration.

#### Instruments/References used

- Check all instruments/references used to determine the diagnosis reported on this registration.
- If the diagnosis type is "No longer meets criteria" or "Misdiagnosis", then check all instruments/references used to determine that diagnostic criteria were not met.

#### **Date First Diagnosed with Autism**

- Date of initial, first ever, Autism diagnosis complete mmddyy date is preferred; however, at least month and year must be reported.
- Same as Today, if this registration is the first ever diagnosis known to Diagnostician or Diagnostician's Practice.
- Unknown, if child previously diagnosed, but date is unknown.

#### Age Symptoms First Noted

 Age, in years or months or a combination, at which anyone, e.g., family member, medical provider, etc., noted symptoms (e.g. communication issues, social issues, restricted/ stereotyped/repetitive behaviors) associated with diagnosis reported on this registration.

#### **Sibling Information**

- Age, in years or months or a combination of each sibling at time of this registration.
- Indicate if the sibling is also diagnosed with an Autism Spectrum Disorder.
- Unknown if age of sibling is unknown

# **AUTISM REGISTRATION – INSTRUCTIONS**

#### **Diagnostician Information**

- Corresponds to the individual who made the actual diagnosis.
- Credential and specialty information is required.
- If the diagnostician's practice is located within NJ, then a complete address should be provided.
- If the diagnostician's practice is located within the U.S., but not in NJ, then at least the city and state must be provided.
- If the diagnostician's practice is located outside of the United States, then at least the country must be provided.

## Person Submitting Report

- Check appropriate box.
- If person other than diagnostician or diagnostician's staff is submitting this registration, then complete practice/facility name and all contact information.

#### Special Child Health Services (SCH-0) Registration Form

- Required component for autism reporting.
- Information to be completed depends upon whether the report is for autism only diagnosis or the report includes other congenital diagnoses normally reported to the State Birth Defects Registry.
- Follow Special Child Health Services (SCH-0) Form instructions unless otherwise noted below.

#### SCH-0 Form Sections to Complete: Autism Only Registration

- Registration Type
  - New registering child as a "First Registration".
  - Update when registering child as a "Revised or Updated Registration".
- Family Informed
- Type of Hospital/Reporting Facility
- Registering Agency Name
- Insurance Type
- Name of Child, Also Known As
- Child's Current Residence Address
- Hospital/Place of Birth
- Primary Care Provider
- Date of Birth
- Sex
- Plurality, Birth Order
- Ethnicity Information, whole section
- Birth Mother's Residence at Time of Birth
  - $\circ\,$  If the birth took place in New Jersey, then report city, county and state.
  - $\circ\;$  If the birth took place in the United States, then report city and state.
  - If the birth took place outside the United States, then report country.
- Death Information
- Parent A Information
- Do not report Ethnicity Information
- Parent B Information
- Guardian Agency Information
- Guardian's Information
- Diagnosis Description for Other Comorbid Diagnoses

#### Autism with Other Congenital Diagnoses

• All sections to be completed as per SCH-0 Form instructions.

#### Non-Identifiable Autism Only Registration

- Applies to Autism Only registrations congenital diagnoses registrations require all information on SCH-0 Form.
- Report all information as above, except:
  - Do NOT report name information for child, parent A, parent B, or individual guardian.
  - Report only county, state, and country address information for the child, parent A, parent B, or individual guardian.
  - o Report only month and year of birth.

# Autism Registrations: Quick Reference Guide on Completing the Forms

# Autism ONLY (no other registerable conditions)

1. Complete the SCH-0 Form (Birth Defects Registration Form) and the SCH-1 Form (Autism Supplemental Information)

AND

- 2. OMIT the following on the SCH-0 form:
  - a. Medical Record #
  - b. Hospital Contact
  - c. Transfer Information
  - d. Street or PO Box information for Birth Mother's Residence at Time of Birth
  - e. Parent A Ethnicity Information

# Anonymous Autism ONLY (no other registerable condition)

1. Complete the SCH-0 Form (Birth Defects Registration Form) and the SCH-1 Form (Autism Supplemental Information)

AND

- 2. OMIT the following on BOTH forms:
  - a. All the Autism ONLY information above PLUS
  - b. Name of Child & Parents/Caregiver
  - c. Mother's residence at the time of birth (all information)
  - d. Address for Parent A, Parent B, and/or Guardian except for county and state.
  - e. The day of the child's date of birth (NOTE: you still need the month and year of the child's date of birth and the parents' date of birth)

# Autism AND Mandatory Condition Registration (i.e., BDR)

1. Complete the SCH-0 Form (Birth Defects Registration Form) and the SCH-1 Form (Autism Supplemental Information)

AND

2. OMIT nothing

# Anonymous Autism AND Mandatory Condition Registration (i.e., BDR)<sup>1</sup>

1. Complete the SCH-0 Form (Birth Defects Registration Form) and the SCH-1 Form (Autism Supplemental Information)

AND

- 2. OMIT the following on the SCH-1 Form (Autism Supplemental Information):
  - a. Name of Child
  - b. Day of the child's date of birth (Note: you still need the month and year of the child's date of birth)

<sup>&</sup>lt;sup>1</sup> NOTE: These forms need to be completed separately for the child so that their information is not linked. Although a registration for autism can be anonymous (with no identifiable information), a BDR registration cannot be anonymous.



# How private is my child's information?

e recognize the sensitivity of your information and respect the rights of all individuals with Autism and their families. We take seriously our obligation to pro-

tect the privacy and confidentiality of individuals and we keep all personal information in a tightly secured location.

# Can you refuse to have your child registered?

o, but you can ask your health care professional not to include your child's personal information such as their name and address on the registration form.

However, if your child's personal information is not included:

- We will not be able to link your child to important services and resources, or your county-based case management unit.
- Your health care provider will need a signed written statement from you for their files,
- Your child's non-identifying information such as sex, month and year of birth, and county of residence will still be registered.

For Questions about the Registry, please call: 609-292-5676

If you need services, visit our website at: http://www.state.nj.us/health/fhs/sch/index.shtml

or

- For children birth to age three with developmental delays and disabilities, please call I-888-653-4463
- For children birth through age 21 with special health care needs, each county's telephone number can be found on our website: <u>http://www.nj.gov/health/fhs/sch/sccase.shtml</u> or by calling 609-777-7778

The Autism Registry is part of the New Jersey Department of Health & Senior Services Division of Family Health Services Special Child Health and Early Intervention Services PO Box 364 Trenton, NJ 08625-0364



# The New Jersey Autism Registry: Information for Families



Chris Christie Governor Kim Guadagno Lt.Governor



Dr. Poonam Alaigh Commissioner



## What is Autism?

utism is a condition that affects a child's development and function in social interactions, communication, and patterns of behavior. In the New Jersey Autism Registry, we include diagnoses commonly

known as the Autism Spectrum Disorders (ASD). These include Asperger Syndrome, Autistic Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), Rett Syndrome and Childhood Disintegrative Disorder. If your child has been diagnosed with one of these conditions they are included in the registry.

# How will my child be registered?

our health care provider will register your child by completing specific forms and submitting them to the Department of Health and Senior Services. Only children who are New Jersey residents and under the age of twenty-two will be registered.

Your provider must inform you about the registry. If you are unsure if your child has been registered and would like to have your child registered, please contact your health care provider.





# What information about my child will be reported to the registry?

he registry will be collecting information such as:

- Your child's name, address, date of birth, gender, and race,
- Your child's diagnosis, when you first noticed symptoms, and when they were diagnosed,
- Information about the provider who made the diagnosis.

# Why is my child's name and personal information being collected?



- You can be referred to the Special Child Health Services Case Management Unit in your county for help with resources.
- If your child's information or diagnosis changes, we are able to update the registry.

# Will I be contacted?

es. Once your child is registered, you will receive a letter and informational pamphlets telling you that your child has been registered, and about services that may be available for you and your family.



A person from your county's Special Child Health Services Case Management Unit will contact your family and inform you of available family-centered services in your community. County-based case management units assist families of children from birth to 21 years of age with special health care needs.

# Why should my child be registered?

ver the last several years there has been an increase in the number of children diagnosed with Autism. While we don't know the reasons for this increase, we also don't know how many more children are being diagnosed and need services. To best serve children with Autism, we need to know how many children are being diagnosed so that we can plan and provide services to them and their families. It's important that your child be registered, so that your family can be notified of these services, many at no charge to the families.

#### New Jersey Department of Health and Senior Services Special Child Health and Early Intervention Services STATE BIRTH DEFECTS REGISTRY PO Box 364, Trenton, NJ 08625-0364

	REGIS	STRATI	ON IN	FORMAT	ION	
Registration Typ				Family Info	ormed	of Registration
New [	]Update [	Audit		🗌 Yes		□No
Type of Hospita	l/Reporting Fa	cility				
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Registering Age	ncy Name					
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Medical Record	Number		E	lectronic Bir	th Cer	rtificate (EIN) No.
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Name of Hospita	al/Agency Con	tact (Las	t, First	, Middle, Su	ffix)	
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Zip Code	County		Cour	ntry		
HOSPITAL / PL	ACE OF BIRT	н				
Medical Facility	Name or Desc	ription of	Locat	ion		
City			State	9	Cour	ntry
-						
				4805		
PRIMARY CAR						
Practice Name -	OR- Provider	Name (La	ast Na	me, First Na	ame)	Undecided
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# SPECIAL CHILD HEALTH SERVICES REGISTRATION

	CHILD'S IN	IFORI	NATION	N, CONT	'INU	ED	
BIRTH INFORM							
Date of Birth	S	Sex	emale	🗌 Ma	le	Indeterminate	
Birthweight	Grams –OR-		Lbs	0	ZS.	-OR- 🗌 Unknown	
Plurality						Birth Order	
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Unit Description		Unit			P.C	). Box	
City					Sta	te	
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DEATH INFORM	MATION FOR C						
Is Expired?	_	Date	e of Deat	h		🗌 Unknown	
🗌 Yes 🗌	] No						
Place of Death Unknown							
Autopsy?					Der	ath Certificate Number	
Yes     No     Pending     Unknown							
PARENT A INFORMATION							
Parent A Vital Status							
🗌 Alive	Dead	Unkno	own				
Sex	☐ Female		Biologi		] No	Unknown	
PARENT A NAM						Suffix	
Last Name						Suffix	
First Name			N	liddle Na	me		
Maiden Name							

# SPECIAL CHILD HEALTH SERVICES REGISTRATION (Continued)

PA	ARENT A IN	FORMA	TION, CON	ITINUED		PAR	ENT B INFO	RMATION, CON	ITINUED	
PARENT A MAILING ADDRESS			Parent B Legal	Guardia	an Status	Date of Bi	rth			
Same as child	d's current	residenc	e address		🗌 Yes [	] No	Unknow	n		
Street Address					Telephone Nur	nber				
					()				No Phone	
Unit Description		Unit		P.O. Box		GL	JARDIAN AG	SENCY INFORM	ATION	
					Legal Guardiar	n Status	Gu	ardian Type		
City				State	🗌 Yes			Relative		
ony				Club		□ No □ Individual (Non-Relative)				
7.0.1					Unknow	/n			Agency (DYFS, etc.)	
Zip Code Cou	unty	Co	untry					Private Agence	;y	
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Parent A Legal Guard			Date of Bi	rth	Agency Name					
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PARENT B NAME										
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PARENT B MAILING	3 ADDRESS				□ Same a	s child's	s current resi	dence address		
Same as child	d's current	residenc	e address							
Street Address					Street Address					
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	STATE USE ONLY		
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## New Jersey Department of Health and Senior Services Special Child Health Services - Registration AUTISM SUPPLEMENTAL INFORMATION

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	DIAG	IOSTIC	IAN INFORM	ATION		
Title ∏Dr.	Name of In	dividual	Making Diagnos	is (Last, Fi	irst)	
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Highest De	•					
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Gene	y Practice ticist blogy bpsychology	erapy	<ul> <li>Pediatrics-Specialty</li> <li>Physical Therapy</li> <li>Psychiatry</li> <li>Psychology</li> <li>Social Work</li> <li>Speech/Language Pathology</li> <li>Other, specify:</li> <li>Unknown</li> </ul>			
PRA	CTICE/FA	CILITY	WHERE DIAC	SNOSIS I	MADE	
Practice/Fa	cility Name					
Departmen	t/Unit					
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Title	Name (Las	t, First)				
□Dr. □Mr. □Ms.						
CONTACT INFORMATION (IF DIFFERENT FROM DIAGNOSTICIAN)						
Practice/Fa	cility Name					
Departmen	t/Unit					
Street Addr	ess					
Unit Descri	ption		Unit		P.O. Box	
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