**Supplementary Tables**

Supplemental Table 1. Attrition tables for 2018 survey

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Total Membership database 1996–March 2018** | **Sent survey invitation\*** | **Completed survey (for unique surveys only)** |
| **Number** | 7,211 | 3,542 | 760 |
| **Sex, *n* (%)**  Male  Female  Unknown | 3,480 (48.3)  3,351 (46.5)  380 (5.3) | 1,716 (48.5)  1,719 (48.5)  107 (3.0) | 345 (45.4)  386 (50.8)  29 (3.8) |
| **Deceased, *n* (%)** | 1,860 (25.8) | 841 (23.7) | 141 (18.6) |
| **Deceased, type I only, *n* (%)** | 1,516 (52.7) | 728 (49.6) | 111 (41.4) |
| **Average age at death, months type I only, *n* (%)** | 18.3 (44.9) | 19.1 (37.9) | 28.2 (54.1) |
| **Resides in US, *n* (%)** | 5,640 (80.1) | 2,587 (73.0) | 529 (85.6) |
| **No. US states represented** | 50 | 50 | 46 |
| **SMA type, *n* (%)**  0  I  II  III  IV  Unknown | 11 (0.2)  2,877 (39.9)  2,133 (29.6)  1,229 (17.0)  230 (3.2)  731 (10.1) | 9 (0.3)  1,469 (41.5)  1,146 (32.4)  624 (17.6)  67 (1.9)  227 (6.4) | 12 (1.6)  268 (35.2)  290 (38.2)  173 (22.8)  5 (0.7)  12 (1.6) |
| **Median (range) age by SMA type, years**  0  I  II  III  IV | Data not collected  7 (0–57)  14 (0–98)  24 (2–83)  55 (20–89) | Data not collected  4 (0–53)  9 (0–98)  17 (2–81)  52 (30–78) | 0  3 (0–43)  11 (1–76)  29 (2–78)  67 (58–78) |
| **Median (range) age at symptom onset by SMA type, months**  0  I  II  III  IV | Data not collected  2 (0–12)  8 (0–18)  26 (3–300)  Data not collected | 1  2 (0–12)  8 (0–18)  26 (3–300)  Data not collected | 0 (0–2)  2 (0–49)  9 (0–160)  18 (0–680)  37.5 (14–420) |
| **Median (range) age at diagnosis by SMA type, months**  0  I  II  III  IV | 1 (0–2)  4 (-8 to 267)  17 (-11 to 590)  56 (-5 to 912)  504 (14–988) | 0.5 (0–2)  4 (-8 to 127)  17 (-9 to 462)  47 (-5 to 912)  458 (14–812) | 2 (0–13)  4 (-16 to 441)  16 (-7 to 344)  60 (-6 to 587)  557.5 (343–664) |
| **Median (range) diagnostic delay, by SMA type, months†**  0  I  II  III  IV | 1  2 (0–9)  7 (0–21)  15 (1–115)  No data | 1  2 (0–9)  7 (0–21)  15 (1–115)  No data | 1 (0–13)  1 (0–437)  6 (0–329)  26 (0–547)  329 (35–619) |

SMA, spinal muscular atrophy; US, United States.

\*760 respondents who completed the survey were not all part of the 3,542 people sent a survey invitation.

†If diagnostic delay was negative (child started to show symptoms after receiving a diagnosis), the negative value was edited to “0” to indicate no diagnostic delay.

Supplemental Table 2. 2017 Member Update Survey

# Community Update Survey

If you have any questions, please feel free to contact [research@curesma.org](mailto:research@curesma.org). As a thank you for your time in completing this survey, everyone who participates will be entered into a drawing for a trip to the 2017 Annual SMA Conference in Disney World, as well as other thank you gifts. Thank you again for your participation.

Information on person completing survey (Survey can only be completed by the affected individual or their parent, legal guardian, or primary caregiver):

1. Name:
2. Email:
3. Street 1:
4. City/State/ZIP:
5. Country:
6. Phone Number:
7. Date of Birth:
8. Your relationship to affected child or individual:

Self

Parent

Grand parent

Relative

Spouse

Friend

Other

1. Are you the primary caregiver (A person who takes primary responsibility for someone who cannot care fully for themselves. May be a family member, a trained professional or another individual)?

Yes

No

For each affected child or affected individual, please complete the following information through the viewpoint of the affected individual

## **Demographics**

1. First Name:
2. Last Name:
3. Street Address:
4. City:
5. State/Province:
6. Zip Code:
7. Country:
8. Email:
9. Primary Phone Number:
10. Birthdate: *mm/dd/yyyy*
11. Marital Status

Married

Common Law (permanent living arrangement with a partner, but not married)

Widowed

Divorced

Single

1. Gender

Male

Female

1. What is your Ethnicity origin (or Race)? If mixed, please choose *other*

White

Black or African American

Native American or American Indian

Hispanic or Latino

Asian/Pacific Islander

Other

If *Other,* please specify:

1. What is the highest degree or level of school you have completed? If currently enrolled, highest degree received. If homeschooled, chose the grade equivalent.

No schooling completed

Pre-school

Kindergarten

First grade

Second grade

Third grade

Fourth grade

Fifth Grade

Sixth Grade

Seventh Grade

Eighth Grade

Some high school, no diploma

High school graduate, diploma or the equivalent (for example: GED)

Some college credit, no degree

Trade/technical/vocational training

Associate degree

Bachelor’s degree

Master’s degree

Professional degree

Doctorate degree

1. Type of SMA

Type I

Type II

Type III

Type IV

Distal

Kennedy's

SMARD

Unknown

1. How many SMN2 Copies do you have?

1

2

3

4

5 or more

Don’t know

1. On what date were you diagnosed? *mm/dd/yyyy*

If diagnosis date is estimated, check here:

1. If you are completing this survey on behalf of an individual that has passed away, please provide the deceased date: *mm/dd/yyy*
2. If the deceased date is estimated, check here:
3. How did you first hear of Cure SMA?

Doctor or other healthcare provider

Family/Friend

Online/Website Search

Other

## **Physician Information**

1. Primary Health Care Provider - Who is your primary health care provider?

Primary Health Care Provider's Full Name:

1. Primary Health Care Provider's Full address: (ie: Street, Suite, City, State, Zip)
2. Primary Health Care Provider's Email address if available:
3. What is your Primary Health Care Provider’s specialty?

Family practice

Internal medicine

Pediatrics

Neurology

Pulmonology

Ob/Gyn

Other

If *Other*, please specify:

1. Please identify all the specialists in your care team (Check all that apply):

☐Neurologist

☐Pulmonologist (Lung doctor)

☐Rehab Medicine/physiatrist

☐Genetics

☐Palliative Care

☐Orthopedics

☐Cardiologist (Heart doctor)

☐Physical therapist

☐Speech therapist

☐Occupational therapist

☐Nutritionist

☐Orthotist

☐Vocational Rehabilitation Counselor

☐Psychologist/Therapist

☐Gastroenterologist (Stomach Doctor)

☐Nephrologist (Kidney Doctor)

☐Endocrinologist (Metabolic Doctor)

☐Social Worker

☐Other

If Other, please specify

## **Health Information**

1. How many times in the past year (last 12 months) have you been admitted to the hospital for a reason related to SMA?
2. What type of surgeries have you EVER had related to SMA?

Scoliosis

Hip surgery

Ankle/Foot surgery

Eye surgery

Gastrostomy

Nissen Fundoplication (stomach wrap to prevent vomiting)

Ileostomy

Colostomy

Dental Surgery

Tonsils

Joint contracture

G-tubes

Tracheotomy

1. Have you EVER fractured or broken a bone? (Check all that apply)

Yes, I have fallen and broken a bone

Yes, I had a stress fracture

Yes, I broke or fractured a bone due to other reasons

No, I have never fractured or broken a bone

Don’t know

1. Do you currently have pain in your back, hip, groin, and/or feet?

All the time

Some of the time

Rarely

Never

Not applicable (N/A)

5. Have you ever participated in a clinical trial for SMA?

Yes

No

Don’t Know

## **Motor Function**

1. What is the maximum motor function you have ever achieved?

☐Head control

☐Roll over completely

☐Maintain seated position supported

☐Maintain seated position unsupported

☐Crawl combat style

☐Crawl 4 point

☐Stand with support

☐Cruise along furniture

☐Stand without support

☐Walk independently

☐None of the above

1. What is your current maximum motor function?

Head control

Roll over completely

Maintain seated position supported

Maintain seated position unsupported

Crawl combat style

Crawl 4 point

Stand with support

Cruise along furniture

Stand without support

Walk independently

None of the above

☐Not applicable (N/A)

## **Nutrition**

1. Do you currently receive any of the following for nutrition? (Check all that apply)

Standard/intact (e.g. Enfamil, Pediasure),

Hydrolyzed (e.g. Nutramigen, Peptamen Jr, Pediasure Peptide)

Elemental (e.g. Elecare, Pediatric Vivonex, Tolerex)

Commercial blenderized formula (e.g. Compleat pediatric, Nourish)

Home blenderized formula

Breast Milk

I’m not on any type of formula

☐Not applicable (N/A)

1. Do you currently have a feeding tube (e.g. G-tube, J-tube, GJ-tube, NG-tube, NJ-tube)?

☐Yes, I’m fed by a gastrostomy tube into the stomach

Yes, I’m fed by Jejunostomy tube into the small intestine

Yes, I’m fed by a nasogastric tube into the stomach

☐No, I don’t have a feeding tube

☐Unknown

☐Not applicable (N/A)

## **Breathing**

1. Do you currently use any of the following? (Choose all that apply)

Oxygen

BiPAP machine

CPAP machine

Cough Machine

Ventilator

Tracheostomy with breathing machine

None, I don’t use any breathing machines

☐Not applicable (N/A)

Other

If *Other,* please specify:

1. How many hours per day do you use oxygen or a breathing machine?

Less than 8 hours per day

8-16 hours per day

More than 16 hours per day

I don’t use oxygen or a breathing machine

Not applicable (N/A)

## **Family/Home Life** (please remember to fill in the following questions through the viewpoint of the SMA affected individual)

1. Do you have any siblings (not including step-brothers/step-sisters)? If yes, please write down their name, age and if they are affected or not affected with SMA.

Sibling 1 Name (First and Last):

Sibling 1 birthdate: *mm/dd/yyyy*

Sibling 1 SMA Status:

Not Affected

Known Carrier of SMA

Affected with SMA

Unknown

If Sibling 1 affected with SMA, please indicate Type of SMA:

Type I

Type II

Type III

Type IV

Distal

Kennedy's

SMARD

Unknown

Sibling 2 Name (First and Last):

Sibling 2 birthdate: *mm/dd/yyyy*

Sibling 2 SMA Status:

Not Affected

Known Carrier of SMA

Affected with SMA

Unknown

If Sibling 2 affected with SMA, please indicate Type of SMA:

Type I

Type II

Type III

Type IV

Distal

Kennedy's

SMARD

Unknown

Sibling 3 Name (First and Last):

Sibling 3 birthdate: *mm/dd/yyyy*

Sibling 3 SMA Status:

Not Affected

Known Carrier of SMA

Affected with SMA

Unknown

If Sibling 3 affected with SMA, please indicate Type of SMA:

Type I

Type II

Type III

Type IV

Distal

Kennedy's

SMARD

Unknown

Sibling 4 Name (First and Last):

Sibling 4 birthdate: *mm/dd/yyyy*

Sibling 4 SMA Status:

Not Affected

Known Carrier of SMA

Affected with SMA

Unknown

If Sibling 4 affected with SMA, please indicate Type of SMA:

Type I

Type II

Type III

Type IV

Distal

Kennedy's

SMARD

Unknown

Sibling 5 Name (First and Last):

Sibling 5 birthdate: *mm/dd/yyyy*

Sibling 5 SMA Status:

Not Affected

Known Carrier of SMA

Affected with SMA

Unknown

If Sibling 5 affected with SMA, please indicate Type of SMA:

Type I

Type II

Type III

Type IV

Distal

Kennedy's

SMARD

Unknown

Sibling 6 Name (First and Last):

Sibling 6 birthdate: *mm/dd/yyyy*

Sibling 6 SMA Status:

Not Affected

Known Carrier of SMA

Affected with SMA

Unknown

If Sibling 6 affected with SMA, please indicate Type of SMA:

Type I

Type II

Type III

Type IV

Distal

Kennedy's

SMARD

Unknown

1. What type of caretakers (other family members, nurses, personal care worker, attendant, in-home aide) care for you? Choose all that apply.

My parent(s)/legal guardian(s) are my full-time caretakers

My spouse is my full-time caretakers

My sibling is my full-time caretakers

Other family members

Nurses

Personal Care Worker

Attendant

In-home aid

Other

If other, please specify:

None

1. About how many hours per week do you have a caretaker, other than a family member?

0-5 hours per week

6-10 hours per week

11-20 hours per week

21-40 hours per week

41-60 hours per week

61-80 hours per week

81-100 hours per week

>100 hours per week

Not applicable (N/A)

1. Are you currently employed or attending school?

Yes, I am employed full-time

Yes, I am employed part-time

Yes, I attend school full-time

Yes, I attend school and am employed

No, I am not employed nor attending school

Not applicable (N/A)

1. What is the estimated annual SMA-related expenses/costs that your family pays directly including copays, deductibles, prescriptions, medical supplies, adapted vehicles, and mobility devices.

Less than $1,000

$1,000-$1,999

$2,000-$2,999

$3,000-$4,999

$5,000-$14,999

$15,000-$19,999

$20,000-$29,999

$30,000-$39,999

$40,000-$49,999

$50,000-$79,999

$80,000-$100,000

Greater than $100,000

☐Unknown

Not applicable (N/A)

Supplemental Table 3.2018 Member Update Survey

**Community Update Survey – Year 2**

If you have any questions, please feel free to contact [research@curesma.org](mailto:research@curesma.org).

**Information on person completing survey (Survey can only be completed by the affected individual or their parent, legal guardian, or primary caregiver):**

1. Name:
2. Email:
3. Street 1:
4. City/State/ZIP:
5. Country:
6. Phone Number:
7. Date of Birth:
8. Your relationship to affected child or individual:

Self

Parent

Grand parent

Relative

Spouse

Friend

Other

1. Are you the primary caregiver (A person who takes primary responsibility for someone who cannot care fully for themselves. May be a family member, a trained professional or another individual)?

Yes

No

For each affected child or affected individual, please complete the following information through the viewpoint of the affected individual

**Demographics**

1. First Name:
2. Last Name:
3. Street Address:
4. City:
5. State/Province:
6. Zip Code:
7. Country:
8. Email:
9. Primary Phone Number:
10. Birthdate: *mm/dd/yyyy*
11. Marital Status

Married

Common Law (permanent living arrangement with a partner, but not married)

Widowed

Divorced

Single

1. Gender

Male

Female

1. What is your Ethnicity origin (or Race)? If mixed, please choose *other*

White

Black or African American

Native American or American Indian

Hispanic or Latino

Asian/Pacific Islander

Other

If *Other,* please specify:

1. What is the highest degree or level of school you have completed? If currently enrolled, highest degree received. If homeschooled, chose the grade equivalent.

No schooling completed

Pre-school

Kindergarten

First grade

Second grade

Third grade

Fourth grade

Fifth Grade

Sixth Grade

Seventh Grade

Eighth Grade

Some high school, no diploma

High school graduate, diploma or the equivalent (for example: GED)

Some college credit, no degree

Trade/technical/vocational training

Associate degree

Bachelor’s degree

Master’s degree

Professional degree

Doctorate degree

1. What is your current height (in inches) and weight (in pounds)? Leave blank if not sure.

Height (inches):

Weight (pounds):

1. Type of SMA

Type 0

Type I

Type II

Type III

Type IV

Distal

Kennedy's

SMARD

Unknown

1. How many SMN2 Copies do you have?

1

2

3

4

5 or more

Don’t know

19. At what age (in months) did you first notice something was wrong? If less than 1 month, please enter 0:

1. On what date were you diagnosed? *mm/dd/yyyy*

If diagnosis date is estimated, check here:

1. If you are completing this survey on behalf of an individual that has passed away, please provide the deceased date: *mm/dd/yyyy*
2. If the deceased date is estimated, check here:
3. How did you first hear of Cure SMA?

Doctor or other healthcare provider

Family/Friend

Online/Website Search

Other

**Physician Information**

1. Primary Health Care Provider - Who is your primary health care provider?

Primary Health Care Provider's Full Name:

1. Primary Health Care Provider's Full address: (ie: Street, Suite, City, State, Zip)
2. Primary Health Care Provider's Email address if available:
3. What is your Primary Health Care Provider’s specialty?

Family practice

Internal medicine

Pediatrics

Neurology

Pulmonology

Ob/Gyn

Other

If *Other*, please specify:

1. Please identify all the specialists in your care team (Check all that apply):

☐Neurologist

☐Pulmonologist (Lung doctor)

☐Rehab Medicine/Physiatrist

☐Genetics

☐Palliative Care

☐Orthopedics

☐Cardiologist (Heart doctor)

☐Physical therapist

☐Speech therapist

☐Occupational therapist

☐Nutritionist

☐Orthotist

☐Vocational Rehabilitation Counselor

☐Psychologist/Therapist

☐Gastroenterologist (Stomach Doctor)

☐Nephrologist (Kidney Doctor)

☐Endocrinologist (Metabolic Doctor)

☐Social Worker

Interventional Radiologist

☐Other

If Other, please specify:

**Health Information**

1. What type of surgeries have you EVER had related to SMA?

Spinal fusion for scoliosis

Spinal rods for scoliosis

MAGEC rods for scoliosis

☐ Vertical expandable prosthetic titanium rib (VEPTR) surgery

Hip surgery

Ankle/Foot surgery

Eye surgery

Gastrostomy

Nissen Fundoplication (stomach wrap to prevent vomiting/aspiration)

Ileostomy

Colostomy

Dental Surgery

Tonsils

Joint contracture

G-tubes

Tracheotomy

Ear tubes placement (myringotomy/tympanostomy)

I have never had surgery related to SMA

Don’t Know

1. If you had scoliosis surgery, at what age did you have the surgery done?
2. How many times in the past year (last 12 months) have you been admitted to the hospital for a reason related to SMA?
3. Why were you hospitalized over the last 12 months? (Check all that apply)

Respiratory distress

Pneumonia

Infection other than pneumonia

Failure to thrive

Dehydration or malnutrition

Feeding tube problems

Abdominal pain

Cardiomyopathy or arrhythmia

Trauma, fracture or external injury

Seizure

Headache

Surgery

Rash

I was not hospitalized over the last 12 months

Other

If Other, please specify:

1. Have you EVER fractured or broken a bone? (Check all that apply)

Yes, I have fallen and broken a bone

Yes, I had a stress fracture

Yes, I broke or fractured a bone due to other reasons

No, I have never fractured or broken a bone

Don’t know

1. Do you currently have pain in your back, hip, groin, and/or feet?

All the time

Some of the time

Rarely

Never

Not applicable (N/A)

1. Have you EVER participated in a clinical trial for SMA?

Yes

No

Don’t Know

1. Have you EVER been treated with the drug, Spinraza (nusinersen)?

Yes, I was in the Spinraza clinical trial or early access program (EAP)

Yes, I am currently being treated with Spinraza that my doctor has prescribed for me

Yes, I am currently being treated with Spinraza and was also in the clinical trial/EAP

Yes, I was previously (but not currently) treated with Spinraza that my doctor prescribed for me

Yes, I was previously (but not currently) treated with Spinraza that my doctor prescribed for me and was also in the clinical trial/EAP

No, I have never been treated with Spinraza

Don’t know

1. If you have not been treated with the drug, Spinraza (nusinersen), what are the reasons? (Check all that apply)

I’m not familiar with Spinraza (nusinersen)

It’s too expensive

My doctor/healthcare center does not administer Spinraza

I’m currently waiting for my insurance to cover Spinraza

I am unable to receive Spinraza due to my scoliosis surgery

☐I don’t want to be treated with Spinraza right now

☐I was told I was not a candidate for Spinraza

Other

If other, please specify

1. Have you EVER been diagnosed or been told by a doctor that you have any of the following conditions? (Check all that apply)

Osteoporosis

Asthma

Tonsillitis

Contractures

☐No, I have never been diagnosed with any of the above conditions

**Motor Function**

1. What was your maximum motor function 24 months ago?

☐Head control

☐Roll over completely

☐Maintain seated position supported

☐Maintain seated position unsupported

☐Crawl combat style

☐Crawl 4 point

☐Stand with support

☐Cruise along furniture

☐Stand without support

☐Walk independently

☐None of the above

1. What is the maximum motor function you have EVER achieved?

☐Head control

☐Roll over completely

☐Maintain seated position supported

☐Maintain seated position unsupported

☐Crawl combat style

☐Crawl 4 point

☐Stand with support

☐Cruise along furniture

☐Stand without support

☐Walk independently

☐None of the above

1. What is your current maximum motor function?

Head control

Roll over completely

Maintain seated position supported

Maintain seated position unsupported

Crawl combat style

Crawl 4 point

Stand with support

Cruise along furniture

Stand without support

Walk independently

None of the above

☐Not applicable (N/A)

**Nutrition**

1. Do you currently receive any of the following for nutrition? (Check all that apply)

Standard/intact (e.g. Enfamil, Pediasure),

Hydrolyzed (e.g. Nutramigen, Peptamen Jr, Pediasure Peptide)

Elemental (e.g. Elecare, Pediatric Vivonex, Tolerex)

Commercial blenderized formula (e.g. Compleat pediatric, Nourish)

Home blenderized formula

Breast Milk

I’m not on any type of formula

☐Not applicable (N/A)

1. Do you currently have a feeding tube (e.g. G-tube, J-tube, GJ-tube, NG-tube, NJ-tube)?

☐Yes, I’m fed by a gastrostomy tube into the stomach

Yes, I’m fed by Jejunostomy tube into the small intestine

Yes, I’m fed by a nasogastric tube into the stomach

☐No, I don’t have a feeding tube

☐Unknown

☐Not applicable (N/A)

**Breathing**

1. Do you currently use any of the following? (Check all that apply)

Oxygen

BiPAP machine

CPAP machine

Cough Machine

Ventilator

Tracheostomy with breathing machine

None, I don’t use any breathing machines

☐Not applicable (N/A)

Other

If *Other,* please specify:

1. How many hours per day do you use oxygen or a breathing machine?

Less than 8 hours per day

8-16 hours per day

More than 16 hours per day

I don’t use oxygen or a breathing machine

Not applicable (N/A)

**Family/Home Life** (please remember to fill in the following questions through the viewpoint of the SMA affected individual)

1. Do you have any siblings (not including step-brothers/step-sisters)? If yes, please write down their name, age and if they are affected or not affected with SMA.

Check here if you do not have any siblings and move on to Question 2.

Sibling 1 Name (First and Last):

Sibling 1 birthdate: *mm/dd/yyyy*

Sibling 1 SMA Status:

Not Affected

Known Carrier of SMA

Affected with SMA

Unknown

If Sibling 1 affected with SMA, please indicate Type of SMA:

Type I

Type II

Type III

Type IV

Distal

Kennedy's

SMARD

Unknown

Sibling 2 Name (First and Last):

Sibling 2 birthdate: *mm/dd/yyyy*

Sibling 2 SMA Status:

Not Affected

Known Carrier of SMA

Affected with SMA

Unknown

If Sibling 2 affected with SMA, please indicate Type of SMA:

Type I

Type II

Type III

Type IV

Distal

Kennedy's

SMARD

Unknown

Sibling 3 Name (First and Last):

Sibling 3 birthdate: *mm/dd/yyyy*

Sibling 3 SMA Status:

Not Affected

Known Carrier of SMA

Affected with SMA

Unknown

If Sibling 3 affected with SMA, please indicate Type of SMA:

Type I

Type II

Type III

Type IV

Distal

Kennedy's

SMARD

Unknown

Sibling 4 Name (First and Last):

Sibling 4 birthdate: *mm/dd/yyyy*

Sibling 4 SMA Status:

Not Affected

Known Carrier of SMA

Affected with SMA

Unknown

If Sibling 4 affected with SMA, please indicate Type of SMA:

Type I

Type II

Type III

Type IV

Distal

Kennedy's

SMARD

Unknown

Sibling 5 Name (First and Last):

Sibling 5 birthdate: *mm/dd/yyyy*

Sibling 5 SMA Status:

Not Affected

Known Carrier of SMA

Affected with SMA

Unknown

If Sibling 5 affected with SMA, please indicate Type of SMA:

Type I

Type II

Type III

Type IV

Distal

Kennedy's

SMARD

Unknown

Sibling 6 Name (First and Last):

Sibling 6 birthdate: *mm/dd/yyyy*

Sibling 6 SMA Status:

Not Affected

Known Carrier of SMA

Affected with SMA

Unknown

If Sibling 6 affected with SMA, please indicate Type of SMA:

Type I

Type II

Type III

Type IV

Distal

Kennedy's

SMARD

Unknown

1. What type of caretakers (other family members, nurses, personal care worker, attendant, in-home aide) care for you? Check all that apply.

My parent(s)/legal guardian(s) are my full-time caretakers

My spouse is my full-time caretakers

My sibling is my full-time caretakers

Other family members

Nurses

Personal Care Worker

Attendant

In-home aid

None

Other

If other, please specify:

1. About how many hours per week do you have a caretaker, other than a family member?

1-5 hours per week

6-10 hours per week

11-20 hours per week

21-40 hours per week

41-60 hours per week

61-80 hours per week

81-100 hours per week

>100 hours per week

Not applicable (N/A)

1. Are you currently employed or attending school?

Yes, I am employed full-time

Yes, I am employed part-time

Yes, I attend school full-time

Yes, I attend school and am employed

No, I am not employed nor attending school

Not applicable (N/A)

1. What are the estimated SMA-related expenses/costs that your family paid out of pocket including copays, deductibles, prescriptions, medical supplies, adapted vehicles, and mobility devices over the past 12 months? These expenses/costs are not what your insurance or a third party pays.

Less than $1,000

$1,000-$1,999

$2,000-$2,999

$3,000-$4,999

$5,000-$9,999

$10,000-$14,999

$15,000-$19,999

$20,000-$29,999

$30,000-$39,999

$40,000-$49,999

$50,000-$79,999

$80,000-$100,000

Greater than $100,000

☐Unknown

Not applicable (N/A)

1. If you live in the United States, what type of health insurance do you have? Check all that apply.

Cigna

Humana

Blue Cross/Blue Shield

Aetna

Kaiser Permanente

UnitedHealthcare

Wellpoint

Medicaid

Medicare

Tricare

☐Don’t Know

I don’t have health insurance

I don’t live in the United States

Other

If *Other*, please specify:

1. How long have you had the above insurance?

Less than 1 year

1-2 years

2-5 years

5-10 years

More than 10 years

Don’t Know

I don’t have health insurance