

SENATE No. 678

The Commonwealth of Massachusetts

PRESENTED BY:

Liz Miranda

To the Honorable Senate and House of Representatives of the Commonwealth of Massachusetts in General Court assembled:

The undersigned legislators and/or citizens respectfully petition for the adoption of the accompanying bill:

An Act to improve sickle cell care.

PETITION OF:

NAME:	DISTRICT/ADDRESS:	
<i>Liz Miranda</i>	<i>Second Suffolk</i>	
<i>Lydia Edwards</i>	<i>Third Suffolk</i>	<i>2/8/2023</i>
<i>Joan B. Lovely</i>	<i>Second Essex</i>	<i>3/15/2023</i>
<i>Nick Collins</i>	<i>First Suffolk</i>	<i>10/4/2023</i>
<i>Pavel M. Payano</i>	<i>First Essex</i>	<i>2/2/2024</i>

SENATE No. 678

By Ms. Miranda, a petition (accompanied by bill, Senate, No. 678) of Liz Miranda and Lydia Edwards for legislation to improve sickle cell care. Financial Services.

The Commonwealth of Massachusetts

**In the One Hundred and Ninety-Third General Court
(2023-2024)**

An Act to improve sickle cell care.

Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:

1 **MEDICAID COVERAGE FOR FERTILITY PRESERVATION SERVICES**

2 SECTION 1. Chapter 118E of the General Laws is hereby amended by inserting after
3 section 10N the following section:

4 Section 10O. (a) For the purposes of this section, the following words shall, unless the
5 context clearly requires otherwise, have the following meanings:-

6 (1) "Iatrogenic infertility", in impairment of fertility by surgery, radiation, chemotherapy,
7 or other medical treatment affecting reproductive organs or processes, including without
8 limitation treatment for sickle cell disease.

9 (2) "Physician", an individual licensed to practice under section 2 of chapter 112.

10 (3) "Qualified enrollee", an individual who:

11 (A) is enrolled in the MassHealth program pursuant to section 9;

12 (B) has been diagnosed with a form of cancer or other disease by a physician;
13 (C) needs treatment for that cancer or other disease that may cause substantial risk of
14 sterility or iatrogenic infertility, including surgery, radiation, or chemotherapy; and
15 (D) has a primary illness that has impaired the patient's fertility and ability to reproduce
16 normally.

17 (4) "Standard Fertility Preservation Services", procedures based upon current evidence-
18 based standards of care established by the American Society for Reproductive Medicine, the
19 American Society of Clinical Oncology, or other national medical associations that follow
20 current evidence-based standards of care, and includes the retrieval and storage of two complete
21 oocyte cycles and the collection and storage of two sperm samples.

22 (b)(1) Before January 1, 2024, the division of medical assistance shall apply for a
23 Medicaid waiver or a state plan amendment with the Centers for Medicare & Medicaid Services
24 of the United States Department of Health and Human Services to implement the coverage
25 described in subsection (b).

26 (2) If the waiver or state plan amendment described in subsection (a) is approved,
27 MassHealth shall provide coverage to a qualified enrollee for standard fertility preservation
28 services.

29 (c) Before November 1, 2025, and before November 1 of each third year after 2025, the
30 division of medical assistance shall calculate the change in state spending attributable to the
31 coverage described in subsection (b)(2), and report this amount to house and senate committees
32 on ways and means

33 Commercial Insurance Coverage for Fertility Preservation Services

34 SECTION 2. (a) Notwithstanding any general or special law to the contrary, any policy,
35 contract or certificate of health insurance subject to chapters 32A, 175, 176A, 176B, 176G, 176I,
36 176J or 176Q of the General Laws must provide coverage for medically necessary expenses for
37 standard fertility preservation services when a necessary medical treatment may directly or
38 indirectly cause iatrogenic infertility to an enrollee.

39 (b) In determining coverage pursuant to this section, an insurer shall not discriminate
40 based on an individual's expected length of life, present or predicted disability, degree of medical
41 dependency, quality of life, or other health conditions, nor based on personal characteristics,
42 including age, sex, sexual orientation, or marital status.

43 (c) For the purposes of this section, the following words shall, unless the context clearly
44 requires otherwise, have the following meanings:-

45 “Iatrogenic infertility”, in impairment of fertility by surgery, radiation, chemotherapy, or
46 other medical treatment affecting reproductive organs or processes, including without limitation
47 treatment for sickle cell disease.

48 “May directly or indirectly cause”, the likely possibility that treatment will cause a side
49 effect of infertility, based upon current evidence-based standards of care established by the
50 American Society for Reproductive Medicine, the American Society of Clinical Oncology, or
51 other national medical associations that follow current evidence-based standards of care.

52 “Standard fertility preservation services”, procedures based upon current evidence-based
53 standards of care established by the American Society for Reproductive Medicine, the American

54 Society of Clinical Oncology, or other national medical associations that follow current
55 evidence-based standards of care, and includes the retrieval and storage of two complete oocyte
56 cycles and the collection and storage of two sperm samples.

57 STATEWIDE SCD STEERING COMMITTEE

58 SECTION 3. (a)(1) Notwithstanding any general or special law to the contrary, there is
59 hereby established a Statewide Steering Committee on Sickle Cell Disease within the department
60 of public health.

61 (2) The Steering Committee under this section shall consist of:

62 (A) two representatives from the Massachusetts Sickle Cell Disease Association
63 including the Executive Director or their designee;

64 (B) three medical professionals from major Sickle Cell Disease treatment centers in the
65 commonwealth who shall be appointed by the commissioner;

66 (C) the Executive Director of the Massachusetts Association of Community Health
67 Workers or their designee;

68 (D) the President of the Massachusetts Chapter of the National Association of Social
69 Workers or their designee;

70 (E) two members who shall be appointed by the commissioner, one of whom shall be an
71 expert on the biology of the disease, and one of whom shall be an expert on the psycho-social
72 aspect of the disease;

73 (F) two representatives of the department of elementary and secondary education who
74 shall be appointed by the commissioner, including one of whom is knowledgeable about the right
75 to comparable education, supportive services and accommodations under section 504 of the
76 Rehabilitation Act of 1973;

77 (G) one representative of the Black and Latino Caucus who shall be appointed by the
78 commissioner;

79 (H) one representative of the Asian Caucus who shall be appointed by the commissioner;

80 (I) two sickle cell disease patients who shall be appointed by the Governor, one of which
81 shall be over 25 years in age and the other shall be between 18 and 25 years in age;

82 (J) a parent of a minor child with sickle cell disease who shall be appointed by the
83 Governor;

84 (K) a parent of a secondary or post-secondary school age youth with sickle cell disease
85 who shall be appointed by the commissioner; and

86 (L) one representative who has a background in racial health disparities who shall be
87 appointed by the Governor.

88 The representatives of nongovernmental organizations shall serve staggered 3-year
89 terms. Vacancies of unexpired terms shall be filled within 60 days by the appropriate appointing
90 authority.

91 (3) The Steering Committee under this section shall:

92 (A) establish institution and community partnerships, including hospitals, and institutions
93 of higher education;

94 (B) establish a statewide network of stakeholders, including parents, home health care
95 providers, school-based nurses, and the Massachusetts Sickle Cell Disease Association who are
96 committed to care for individuals with sickle cell disease collaboratively in an inclusive setting;

97 (C) establish a statewide network of racially and culturally competent stakeholders who
98 include general and special education administrators and teachers and paraprofessionals;

99 (D) oversee the development of educational materials for individuals with sickle cell
100 disease, the public, and health care providers about the assistance available to such individuals in
101 the commonwealth, including local school district responsibilities for care of such individuals;

102 (E) identify funding sources for implementing or supporting the actions, studies, policies
103 required by federal and state laws and regulations, or recommended by the Steering Committee,
104 including funding from:

105 (i) state, federal, and local government sources; and

106 (ii) private sources;

107 (F) investigate and report on a standard of basic, multidisciplinary care for patients across
108 the commonwealth; and

109 (G) establish subcommittees as appropriate.

110 (4) The department may, in consultation with the Statewide Steering Committee, provide
111 services relating to sickle cell disease, including:

112 (A) educational programs on sickle cell disease for individuals affected by the disease,
113 including:

- 114 (i) education on the rights of individuals with sickle cell disease, such as, without
115 limitation, the right not to be discriminated against and the right to receive appropriate
116 educational programming, health related services and accommodations necessary to access such
117 programming and services;
- 118 (ii) expectations, options, and responsibilities of families of individuals with sickle cell
119 disease;
- 120 (iii) challenges and responsibilities of caregivers of individuals with sickle cell disease;
- 121 (iv) obligations of employees at primary and secondary schools; and
- 122 (v) challenges and responsibilities of health care providers;

123 (B) social services support to individuals with sickle cell disease, including support from
124 social workers and community health workers to provide information on services that may be
125 available to the individual;

126 (C) hemoglobin electrophoresis or genetic testing for the presence of sickle cell disease;

127 (D) genetic counseling;

128 (E) assistance with any available reimbursement for medical expenses related to sickle
129 cell disease;

130 (F) education and counseling services for parents and other family members and
131 caretakers after the receipt of sickle cell trait test results from the Newborn Screening Program as

132 required by section 270.006(A)(2)(e) of chapter 105, Code of Massachusetts Regulations,
133 provided that, with the consent of parents and other family members and caretakers, such
134 services may be provided in whole or in part by the Massachusetts Sickle Cell Disease
135 Association; and

136 (G) any other programs or services that are necessary to decrease the use of acute care
137 services by individuals who have sickle cell disease.

138 (5) The department shall, in consultation with any other agency of the commonwealth as
139 the department determines appropriate, provide the services in paragraph (4) through
140 community-based organizations, including specifically, pre-K, elementary and secondary
141 schools as well as institutions for higher education for all affected school-age children, youth,
142 and older students to the extent practicable.

143 (6) The Steering Committee, in conjunction with the department and other relevant
144 stakeholders, shall study and make recommendations on:

145 (A) how to enhance access to services for individuals with sickle cell disease with a focus
146 on areas in the commonwealth where there is a statistically high number of individuals with
147 sickle cell disease or in areas where there is a lack of providers with expertise in treating sickle
148 cell disease;

149 (B) whether to establish a sickle cell disease registry, and if recommended, the process
150 and guidelines for establishing a registry and obtaining information consistent with informed
151 consent and protecting data privacy;

152 (C) how to enhance the coordination of health care services for individuals with sickle
153 cell disease who are transitioning from pediatric to adult health care, including the identification
154 of available resources for individuals who are transitioning; and

155 (D) how to engage with community-based health fairs and other community-sponsored
156 events in areas with a statistically high number of individuals with sickle cell disease to provide
157 outreach and education on living with sickle cell disease and how to access health care services.

158 (b) The department shall, in consultation with the Steering Committee, establish and
159 implement a system that provides information on the sickle cell trait to any individual who has
160 the sickle cell trait and, if the individual is a minor, to the individual's family.

161 (c) The department shall include the following in the information provided under
162 subsection (b):

163 (1) how the sickle cell trait impacts the health of an individual with the trait;

164 (2) how the sickle cell trait is passed from a parent to a child; and

165 (3) implications for pregnancy.

166 (d) The department shall maintain in a conspicuous location on its website a list of
167 resources for health care practitioners to use to improve their understanding and clinical
168 treatment of individuals with sickle cell disease or the sickle cell trait, including information on
169 the health impacts of carrying the sickle cell trait.

170 (e) For the purposes of this section, the following word shall, unless the context clearly
171 requires otherwise, have the following meaning:-

172 “Steering Committee”, the Statewide Steering Committee on Sickle Cell Disease.

173 SICKLE CELL DISEASE DETECTION AND EDUCATION PROGRAM (ADULT
174 SCREENING AND EDUCATION- RELATED GRANTS)

175 SECTION 4. (a) Notwithstanding any general or special law to the contrary, there is
176 hereby established within the department of public health the sickle cell disease detection and
177 education program to: (1) promote screening and detection of sickle cell disease, especially
178 among unserved or underserved populations; (2) educate the public regarding sickle cell disease
179 and the benefits of early detection; and (3) provide counseling and referral services.

180 (b) The program under this section shall include:

181 (1) establishment of a statewide public education and outreach campaign to publicize
182 evidence-based sickle cell disease screening, detection and education services. The campaign
183 shall include: general community education, outreach to specific underserved populations,
184 evidence based clinical sickle cell disease screening services, and an informational summary that
185 shall include an explanation of the importance of clinical examinations and what to expect during
186 clinical examinations and sickle cell disease screening services;

187 (2) provision of grants to approved organizations pursuant to subsection (c) and for
188 community based organizations pursuant to subsection (d);

189 (3) compilation of data concerning the program and dissemination of such data to the
190 public; and

191 (4) development of health care professional education programs including the benefits of
192 early detection of sickle cell disease and clinical examinations, the recommended frequency of

193 clinical examinations and sickle cell disease screening services, and professionally recognized
194 best practices guidelines.

195 (c)(1) Under the program, the commissioner of public health shall make grants in
196 amounts appropriated to approved organizations for the provision of services relating to the
197 evidence-based screening and detection of sickle cell disease as part of this program. The
198 services required to be provided under such grants shall include:

199 (A) promotion and provision of early detection of sickle cell disease, including clinical
200 examinations and sickle cell disease screening services;

201 (B) provision of counseling and information on treatment options and referral for
202 appropriate medical treatment;

203 (C) dissemination of information to unserved and underserved populations as determined
204 by the commissioner, to the general public and to health care professionals concerning sickle cell
205 disease, the benefits of early detection and treatment, and the availability of sickle cell disease
206 screening services at no cost to such populations;

207 (D) identification of local sickle cell disease screening services within the approved
208 organization's region;

209 (E) provision of information, counseling and referral services to individuals diagnosed
210 with sickle cell disease; and

211 (F) provision of information regarding the availability of medical assistance, including
212 medical assistance for an individual who is eligible for such assistance pursuant to section 9 of

213 chapter 118E of the General Laws, to an individual who requires treatment for sickle cell
214 disease.

215 (2) The commissioner shall give notice and provide opportunity to submit applications
216 for grants under the program. In order to be considered for a grant, an applicant must show
217 evidence of the following, relating to the services the applicant proposes to provide:

218 (A) ability to provide and to ensure consistent and quality services under the program;

219 (B) expertise in providing the service;

220 (C) capacity to coordinate services with physicians, hospitals and other appropriate local
221 institutions or agencies;

222 (D) ability to provide the service to unserved or underserved populations; and

223 (E) ability to provide the service in accordance with the standards specified in
224 subdivision three of this section.

225 Applications shall be made on forms provided by the commissioner.

226 (3) The commissioner shall develop standards for the implementation of grants under the
227 program by approved organizations, which shall ensure the following:

228 (A) integration of the approved organization with existing health care providers;

229 (B) maximizing third party reimbursement; and

230 (C) provision of services to unserved or underserved populations.

231 (4) Within the amounts of state or federal funds appropriated for the program, approved
232 organizations may be authorized by the department to provide such services for populations
233 served under this title. Services may include evidence based screening, patient education,
234 counseling, follow-up and referral.

235 (5) Every organization receiving grants under this subsection shall submit to the
236 commissioner, on or before October first of each year, a report of such organization's activities,
237 including an assessment of the organization's programs and such data as the commissioner deems
238 relevant and necessary to accomplish the purposes of the program

239 (d)(1) Under the program, the commissioner shall make grants within amounts
240 appropriated for community based organizations to provide post-diagnosis counseling, education
241 and outreach programs for persons diagnosed with sickle cell disease based upon criteria to be
242 developed by the commissioner.

243 (2) The commissioner shall provide notice and opportunity for community-based
244 organizations to submit applications to provide post-diagnosis sickle cell disease counseling,
245 education and outreach programs. Such applications shall be on forms established by the
246 commissioner.

247 (e) The commissioner shall submit, on or before December first of each year, an annual
248 report to the governor and the legislature concerning the operation of the program. The reports
249 shall include the experience of the program in providing services under this act. The annual
250 report shall include strategies for implementation of the sickle cell disease awareness program
251 and for promoting the awareness program to the general public, state and local elected officials,
252 and various public and private organizations, associations, businesses, industries, and agencies.

253 Organizations receiving grants under this act shall provide data and assessments as the
254 commissioner may require for the report. The report shall include any recommendations for
255 additional action to respond to the incidence of sickle cell disease in the commonwealth.

256 (f) For the purposes of this section, the following words shall, unless the context clearly
257 requires otherwise, have the following meanings:-

258 “Community-based organizations”, free-standing organizations in which sickle cell
259 disease survivors hold significant decision-making responsibility, and which offer a broad range
260 of sickle cell disease education and support services free of charge.

261 “Program”, sickle cell disease detection and education program.

262 “Unserved or underserved populations”, people having inadequate access and financial
263 resources to obtain sickle cell disease screening and detection services, including people who
264 lack health coverage or whose health coverage is inadequate or who cannot meet the financial
265 requirements of their coverage for accessing detection services.

266 SCD REGISTRY AND REPORTS- COMPREHENSIVE DATA COLLECTION ON
267 PEOPLE LIVING WITH SCD OR ITS VARIANTS

268 SECTION 5. (a)(1) Notwithstanding any general or special law to the contrary, the
269 commissioner of public health or designee shall, in accordance with regulations adopted by the
270 department of public health pursuant to subsection (b), and in consultation with the
271 Massachusetts Sickle Cell Disease Association, establish and maintain a system for the reporting
272 of information on sickle cell disease and its variants. Said system shall include a record of the
273 cases of sickle cell disease and its variants which occur in the commonwealth along with such

274 information concerning the cases as may be appropriate to form the basis for: (A) conducting
275 comprehensive epidemiologic surveys of sickle cell disease and its variants in the
276 commonwealth; and (B) evaluating the appropriateness of measures for the treatment of sickle
277 cell disease and its variants.

278 (2) Hospitals, medical laboratories, and other facilities that provide screening, diagnostic
279 or therapeutic services to patients with respect to sickle cell disease and its variants shall report
280 the information prescribed by the regulation promulgated pursuant to subsection (b).

281 (3) Any provider of health care who diagnoses or provides treatment for sickle cell
282 disease and its variants, except for cases directly referred to the provider or cases that have been
283 previously admitted to a hospital, medical laboratory or other facility described in paragraph (2),
284 shall report the information prescribed by the regulation adopted pursuant to subsection (b).

285 (b) The department of public health shall, by regulation:

286 (1) prescribe the form and manner in which information on cases of sickle cell disease
287 and its variants must be reported in compliance with any applicable federal privacy law;

288 (2) prescribe the information that must be included in each report, which must include,
289 without limitation: (A) the name, address, age and ethnicity of the patient; (B) the variant of
290 sickle cell disease with which the person has been diagnosed; (C) the method of treatment; (D)
291 any other diseases from which the patient suffers; (E) information concerning the usage of and
292 access to health care services by the patient; and (F) if a patient diagnosed with sickle cell
293 disease and its variants dies, his or her age at death and cause of death; and

294 (3) establish a protocol for allowing appropriate access to and preserving the
295 confidentiality of the records of patients needed for research into sickle cell disease and its
296 variants;

297 (4) establish a protocol for allowing information, in accordance with the preceding
298 subsections, to be communicated with Statewide Steering Committee on Sickle Cell Disease, the
299 sickle cell disease services program, and within the department as determined appropriate by the
300 commissioner.

301 (c) The chief administrative officer of each health care facility in the commonwealth shall
302 make available to the commissioner or designee the records of the health care facility for each
303 case of sickle cell disease and its variants. The department of public health shall abstract from
304 the records of a health care facility or shall require a health care facility to abstract from its own
305 records such information as is required by regulations promulgated pursuant to subsection (b).
306 The department shall compile the information in a timely manner and not later than 6 months
307 after receipt of the abstracted information from the health care facility. The department shall by
308 regulation adopt a schedule of fees which must be assessed to a health care facility for each case
309 from which information is abstracted by the department. Any person who violates this section is
310 subject to an administrative penalty established by regulation by the department.

311 (d) The department shall publish reports based upon the information obtained pursuant to
312 subsections (a), (b), and (c) and shall make other appropriate uses of the information to report
313 and assess trends in the usage of and access to health care services by patients with sickle cell
314 disease and its variants in a particular area or population, advance research and education

315 concerning sickle cell disease and its variants and improve treatment of sickle cell disease and its
316 variants and associated disorders. The reports must include, without limitation:

317 (1) information concerning the locations in which patients diagnosed with sickle cell
318 disease and its variants reside, the demographics of such patients and the utilization of health
319 care services by such patients;

320 (2) the information described in paragraph (1), specific to patients diagnosed with sickle
321 cell disease and its variants who are over 60 years of age or less than 5 years of age; and

322 (3) information on the transition of patients diagnosed with sickle cell disease and its
323 variants from pediatric to adult care upon reaching 18 years of age.

324 (e) The department shall provide any qualified researcher whom the department
325 determines is conducting valid scientific research with data from the reported information upon
326 the researcher's: (1) compliance with appropriate conditions as established under the regulations
327 of the department; and (2) payment of a fee established by the department by regulation to cover
328 the cost of providing the data.

329 (f) The commissioner or designee shall analyze the information obtained pursuant to
330 subsections (a), (b) and (c) and the reports published pursuant to subsection (d) to determine
331 whether any trends exist in the usage of and access to health care services by patients with sickle
332 cell disease and its variants in a particular area or population.

333 (g) If the commissioner or designee determines that a trend exists in the usage of and
334 access to health care services by patients with sickle cell disease and its variants in a particular
335 area or population, the commissioner or designee shall work with appropriate governmental,

336 educational and research entities to investigate the trend, advance research in the trend and
337 facilitate the treatment of sickle cell disease and its variants and associated disorders.

338 (h) The department shall not reveal the identity of any patient, physician, or health care
339 facility which is involved in any reporting required by this section unless the patient, physician
340 or health care facility gives prior written consent to such a disclosure. A person or governmental
341 entity that provides information to the department pursuant to this section shall not be held liable
342 in a civil or criminal action for sharing confidential information unless the person or organization
343 has done so in bad faith or with malicious purpose.

344 (i) For the purposes of this section, the following words shall, unless the context clearly
345 requires otherwise, have the following meanings:-

346 “Sickle cell disease and its variants”, an inherited disease caused by a mutation in a gene
347 for hemoglobin in which red blood cells have an abnormal crescent shape that causes them to
348 block small blood cells and die sooner than normal.

349 SCD REGISTRY AND REPORTS- DATA COLLECTION ON SCD TRAIT

350 SECTION 6. (a)(1) Notwithstanding any general or special law to the contrary, if a
351 newborn screening for hereditary disorders performed pursuant to section 270.006(A)(2)(e) of
352 chapter 105, Code of Massachusetts Regulations detects the presence of sickle cell trait, the
353 laboratory performing the screening shall notify the physician responsible for the newborn’s care
354 and shall document the patient’s information in the central registry established pursuant to
355 paragraph (2) in a manner and on forms prescribed by the department of public health.

356 (2) The physician responsible for such newborn's care shall provide the patient's parents
357 with information concerning the availability, benefits, and role of genetic counseling performed
358 by a genetic counselor licensed pursuant to section 253 of chapter 112 of the General Laws,
359 including a document available in multiple languages (as determined by the department) that
360 identifies at least 10 genetic counselors and the public health care payers and private health care
361 payers which contract with each such genetic counselor. In the case a physician described in the
362 preceding sentence is not identified, the laboratory described in paragraph (1) shall provide the
363 patient's parents with such information relating to genetic counseling. Genetic counseling
364 concerning a diagnosis of sickle cell trait shall include, but not be limited to, information
365 concerning the fact that one or both of the parents carries sickle cell trait and the risk that other
366 children born to the parents may carry sickle cell trait or may be born with sickle cell disease.

367 (b)(1) The commissioner of public health shall establish a central registry of patients
368 diagnosed with sickle cell trait. The information in the central registry shall be used for the
369 purposes of compiling statistical information and assisting the provision of follow-up counseling,
370 intervention, and educational services to patients and to the parents of patients who are listed in
371 the registry including, but not limited to, information concerning the availability and benefits of
372 genetic counseling performed by a genetic counselor licensed pursuant to section 253 of chapter
373 112 of the General Laws.

374 (2) The commissioner shall establish a system to notify the parents of patients who are
375 listed in the registry that follow-up consultations with a physician are recommended for children
376 diagnosed with sickle cell trait. Such notifications shall be provided: at least once when the
377 patient is in early adolescence, when the patient may begin to participate in strenuous athletic
378 activities that could result in adverse symptoms for a person with sickle cell trait; at least once

379 during later adolescence, when the patient should be made aware of the reproductive
380 implications of sickle cell trait; and at such other intervals as the commissioner may require.

381 (3) The commissioner shall establish a system under which the department shall make
382 reasonable efforts to notify patients listed in the registry who reach the age of 18 years of the
383 patient's inclusion in the registry and of the availability of educational services, genetic
384 counseling, and other resources that may be beneficial to the patient.

385 (4) Information on newborn infants and their families compiled pursuant to this section
386 may be used by the department and agencies designated by the commissioner of public health for
387 the purposes of carrying out this act, but otherwise the information shall not be a public record
388 and shall be confidential and not divulged or made public so as to disclose the identity of any
389 person to whom it relates, except as exempted or consented in accordance with section 10 of
390 chapter 66 or section 70G of chapter 111 of the General Laws, respectively.

391 DEVELOPMENT OF A COMPREHENSIVE SCD DISEASE QUALITY STRATEGY
392 IN MEDICAID MANAGED CARE

393 SECTION 7. (a) Notwithstanding any general or special law to the contrary, the division
394 of medical assistance shall ensure the availability of accessible, quality health care for
395 individuals with sickle cell disease who are enrolled in Medicaid managed care organizations or
396 accountable care organizations that have a contract with the division to provide services to
397 individuals enrolled under MassHealth pursuant to section 9 of chapter 118E of the General
398 Laws. Such health care shall include, but not be limited to the following:

399 (1) comprehensive integrated care management for sickle cell disease, including primary
400 care, specialized care, and mental health services;

401 (2) sickle cell trait testing and genetic counseling;

402 (3) social work services as well as education on disease management to patients,
403 caregivers, and providers; and

404 (4) support navigating health insurance coverage and support with transportation to
405 treatment centers.

406 (b) Not later than the fiscal year 2024 contract year, the division of medical assistance
407 shall require Medicaid managed care or accountable care organizations to implement a sickle cell
408 disease quality strategy for children and adults with sickle cell disease that includes, but is not
409 limited to, the following components:

410 (1) measurable goals to improve the identification of members with sickle cell disease
411 within 90 days after enrolling in the contracted health plan;

412 (2) to the extent practicable, adequate provider network capacity to ensure timely access
413 to sickle cell disease specialty service providers, including, but not limited to, hematologists;

414 (3) care coordination strategies and supports to help members with sickle cell disease
415 access sickle cell disease specialists and other related care supports;

416 (4) delivery of a training curriculum approved by the division of medical assistance to
417 educate primary care providers on sickle cell disease, including information on emergency
418 warning signs and complications, evidence-based practices and treatment guidelines, and when
419 to make referrals to specialty sickle cell disease treatment providers; and

420 (5) in the case of an individual who is diagnosed with sick cell disease, exceptions to
421 otherwise applicable prior authorization or dispensing limits for pain medications that are

422 designed to reduce barriers for such an individual to be able to obtain the appropriate dosage and
423 amount of a pain medication in a timely manner.

424 (c) The division of medical assistance shall also do the following:

425 (1) Not later than the fiscal year 2025 contract year, require each Medicaid managed care
426 organization and accountable care organization to report, on a quarterly basis, an unduplicated
427 count of children and adults identified as having sickle cell disease enrolled with the contracted
428 plan during the quarter. The department shall publish these reports, by contracted plan, on the
429 department's website.

430 (2) Not later than January 1, 2025, and in partnership with Medicaid managed care
431 organizations and accountable care organizations, identify, document, and share best practices
432 regarding sickle cell disease care management and care coordination with Medicaid-enrolled
433 primary care and sickle cell disease specialty providers with a goal of improving services for
434 members with sickle cell disease and their families.

435 (3) Enter into a contract not later than January 1, 2025, with a publicly funded university
436 to develop a sickle cell disease-focused comprehensive assessment tool or a supplement to an
437 existing comprehensive assessment tool to screen members identified with sickle cell disease for
438 comorbidities, medical history for the treatment of sickle cell disease including disease-
439 modifying medications and pain management, psychosocial history, barriers to accessing or
440 completing treatments, social supports, other care coordinators working with the member,
441 community resources being used or needed, quality of life, and personal preferences for
442 engagement with a care coordinator.

443 (4) Not later than the fiscal year 2025 contract year, establish performance measures
444 relative to access to care and available therapies, engagement in treatment, and outcomes for
445 individuals with sickle cell disease, with the metrics to be reported annually by the
446 comprehensive health care program to Medicaid managed care organizations and accountable
447 care organizations and with incentive payments attached to the measures.

448 (5) Not later than January 1, 2025, develop a plan for improving the transition from
449 pediatric care to adult care for adolescents with sickle cell disease who are aging out of the
450 Medicaid program, and a plan for helping qualified beneficiaries maintain Medicaid coverage
451 under another eligibility category, in order to maintain continuity of care.

452 (d) The division of medical assistance shall provide an annual sickle cell disease
453 management and accountability report to the senate and house committees on ways and means,
454 including the status of sickle cell disease-focused access to care, quality of services, health
455 outcomes, and disparities in the commonwealth.

456 (e) The division of medical assistance shall incorporate the sickle cell disease
457 management and accountability standards into its contracts with managed care plans and
458 accountable care organizations, including financial or administrative penalties for lack of
459 performance. Contracted plan rates must be adjusted to reflect enhanced care or other provisions
460 that are shifted to the contracted plans.