

HOUSE No. 1161

The Commonwealth of Massachusetts

PRESENTED BY:

Bud L. Williams and David M. Rogers

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:	DATE ADDED:
<i>Bud L. Williams</i>	<i>11th Hampden</i>	<i>1/19/2023</i>
<i>David M. Rogers</i>	<i>24th Middlesex</i>	<i>1/19/2023</i>
<i>Rob Consalvo</i>	<i>14th Suffolk</i>	<i>2/9/2023</i>
<i>Samantha Montaño</i>	<i>15th Suffolk</i>	<i>4/3/2023</i>
<i>Christopher J. Worrell</i>	<i>5th Suffolk</i>	<i>9/5/2023</i>
<i>Jessica Ann Giannino</i>	<i>16th Suffolk</i>	<i>9/5/2023</i>
<i>Carmine Lawrence Gentile</i>	<i>13th Middlesex</i>	<i>9/5/2023</i>
<i>Dawne Shand</i>	<i>1st Essex</i>	<i>9/5/2023</i>
<i>Kate Donaghue</i>	<i>19th Worcester</i>	<i>9/5/2023</i>
<i>Brian M. Ashe</i>	<i>2nd Hampden</i>	<i>10/19/2023</i>
<i>Russell E. Holmes</i>	<i>6th Suffolk</i>	<i>10/19/2023</i>
<i>Brandy Fluker Oakley</i>	<i>12th Suffolk</i>	<i>12/14/2023</i>
<i>Erika Uyterhoeven</i>	<i>27th Middlesex</i>	<i>12/19/2023</i>
<i>Mindy Domb</i>	<i>3rd Hampshire</i>	<i>2/5/2024</i>

HOUSE No. 1161

By Representatives Williams of Springfield and Rogers of Cambridge, a petition (accompanied by bill, House, No. 1161) of Bud L. Williams, David M. Rogers and Rob Consalvo for legislation to to improve sickle cell disease 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 SECTION 1. Chapter 118E of the General Laws is hereby amended by inserting after
2 section 10N the following section:

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

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

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

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

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

11 (B) has been diagnosed with a form of cancer or other disease by a physician;

12 (C) needs treatment for that cancer or other disease that may cause substantial risk of
13 sterility or iatrogenic infertility, including surgery, radiation, or chemotherapy; and

14 (D) has a primary illness that has impaired the patient's fertility and ability to reproduce
15 normally.

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

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

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

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

32 Commercial Insurance Coverage for Fertility Preservation Services

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

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

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

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

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

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

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

56 STATEWIDE SCD STEERING COMMITTEE

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

105 (ii) private sources;

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

108 (G) establish subcommittees as appropriate.

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

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

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

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

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

126 (D) genetic counseling;

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

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

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

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

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

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

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

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

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

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

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

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

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

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

164 (3) implications for pregnancy.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

218 (B) expertise in providing the service;

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

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

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

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

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

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

228 (B) maximizing third party reimbursement; and

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

348 SCD REGISTRY AND REPORTS- DATA COLLECTION ON SCD TRAIT

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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