

HOUSE No.

The Commonwealth of Massachusetts

PRESENTED BY:

Bud L. Williams

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>1/14/2025</i> |

HOUSE No.

[Pin Slip]

The Commonwealth of Massachusetts

**In the One Hundred and Ninety-Fourth General Court
(2025-2026)**

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 Chapter 118E of the General Laws is hereby amended by inserting after section 10Q, the
2 following section:

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

5 “Directly or indirectly cause impairment of fertility”, to cause circumstances where a
6 disease or the necessary treatment for a disease has a likely side effect of infertility as established
7 by the American Society for Reproductive Medicine, the American Society of Clinical Oncology
8 or other reputable professional organizations.

9 “Standard fertility preservation services”, procedures or treatments to preserve fertility as
10 recommended by a board-certified obstetrician gynecologist, reproductive endocrinologist or
11 other physician; provided, however, that the recommendation shall be made in accordance with
12 current medical practices and professional guidelines published by the American Society for

13 Reproductive Medicine, the American Society of Clinical Oncology or other reputable
14 professional organizations.

15 (b) The division and its contracted health insurers, health plans, health maintenance
16 organizations, behavioral health management firms and third-party administrators under contract
17 to a Medicaid managed care organization or primary care clinician plan shall provide coverage
18 for standard fertility preservation services, including, but not limited to, coverage for
19 procurement, cryopreservation and storage of gametes, embryos or other reproductive tissue,
20 when the covered person has a diagnosed medical or genetic condition that may directly or
21 indirectly cause impairment of fertility by affecting reproductive organs or processes. Coverage
22 shall be provided to the same extent that coverage is provided for other pregnancy-related
23 procedures.

24 STATEWIDE SCD STEERING COMMITTEE

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

73 (ii) private sources;

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

76 (G) establish subcommittees as appropriate.

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

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

81 (i) education on the rights of individuals with sickle cell disease, such as, without
82 limitation, the right not to be discriminated against and the right to receive appropriate
83 educational programming, health related services and accommodations necessary to access such
84 programming and services;

85 (ii) expectations, options, and responsibilities of families of individuals with sickle cell
86 disease;

87 (iii) challenges and responsibilities of caregivers of individuals with sickle cell disease;

88 (iv) obligations of employees at primary and secondary schools; and

89 (v) challenges and responsibilities of health care providers;

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

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

94 (D) genetic counseling;

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

97 (F) education and counseling services for parents and other family members and
98 caretakers after the receipt of sickle cell trait test results from the Newborn Screening Program as
99 required by section 270.006(A)(2)(e) of chapter 105, Code of Massachusetts Regulations,
100 provided that, with the consent of parents and other family members and caretakers, such
101 services may be provided in whole or in part by the Massachusetts Sickle Cell Disease
102 Association; and

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

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

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

112 (A) how to enhance access to services for individuals with sickle cell disease with a focus
113 on areas in the commonwealth where there is a statistically high number of individuals with

114 sickle cell disease or in areas where there is a lack of providers with expertise in treating sickle
115 cell disease;

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

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

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

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

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

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

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

132 (3) implications for pregnancy.

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

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

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

140 SICKLE CELL DISEASE DETECTION AND EDUCATION PROGRAM (ADULT
141 SCREENING AND EDUCATION- RELATED GRANTS)

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

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

148 (1) establishment of a statewide public education and outreach campaign to publicize
149 evidence-based sickle cell disease screening, detection and education services. The campaign
150 shall include: general community education, outreach to specific underserved populations,
151 evidence based clinical sickle cell disease screening services, and an informational summary that
152 shall include an explanation of the importance of clinical examinations and what to expect during
153 clinical examinations and sickle cell disease screening services;

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

156 (3) compilation of data concerning the program and dissemination of such data to the
157 public; and

158 (4) development of health care professional education programs including the benefits of
159 early detection of sickle cell disease and clinical examinations, the recommended frequency of
160 clinical examinations and sickle cell disease screening services, and professionally recognized
161 best practices guidelines.

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

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

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

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

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

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

178 (F) provision of information regarding the availability of medical assistance, including
179 medical assistance for an individual who is eligible for such assistance pursuant to section 9 of
180 chapter 118E of the General Laws, to an individual who requires treatment for sickle cell
181 disease.

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

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

186 (B) expertise in providing the service;

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

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

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

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

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

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

196 (B) maximizing third party reimbursement; and

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

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

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

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

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

214 (e) The commissioner shall submit, on or before December first of each year, an annual
215 report to the governor and the legislature concerning the operation of the program. The reports
216 shall include the experience of the program in providing services under this act. The annual
217 report shall include strategies for implementation of the sickle cell disease awareness program
218 and for promoting the awareness program to the general public, state and local elected officials,
219 and various public and private organizations, associations, businesses, industries, and agencies.
220 Organizations receiving grants under this act shall provide data and assessments as the
221 commissioner may require for the report. The report shall include any recommendations for
222 additional action to respond to the incidence of sickle cell disease in the commonwealth.

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

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

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

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

233 SCD REGISTRY AND REPORTS- COMPREHENSIVE DATA COLLECTION ON
234 PEOPLE LIVING WITH SCD OR ITS VARIANTS

235 SECTION 5. (a)(1) Notwithstanding any general or special law to the contrary, the
236 commissioner of public health or designee shall, in accordance with regulations adopted by the
237 department of public health pursuant to subsection (b), and in consultation with the
238 Massachusetts Sickle Cell Disease Association, establish and maintain a system for the reporting
239 of information on sickle cell disease and its variants. Said system shall include a record of the
240 cases of sickle cell disease and its variants which occur in the commonwealth along with such
241 information concerning the cases as may be appropriate to form the basis for: (A) conducting
242 comprehensive epidemiologic surveys of sickle cell disease and its variants in the
243 commonwealth; and (B) evaluating the appropriateness of measures for the treatment of sickle
244 cell disease and its variants.

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

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

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

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

255 (2) prescribe the information that must be included in each report, which must include,
256 without limitation: (A) the name, address, age and ethnicity of the patient; (B) the variant of

257 sickle cell disease with which the person has been diagnosed; (C) the method of treatment; (D)
258 any other diseases from which the patient suffers; (E) information concerning the usage of and
259 access to health care services by the patient; and (F) if a patient diagnosed with sickle cell
260 disease and its variants dies, his or her age at death and cause of death; and

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

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

268 (c) The chief administrative officer of each health care facility in the commonwealth shall
269 make available to the commissioner or designee the records of the health care facility for each
270 case of sickle cell disease and its variants. The department of public health shall abstract from
271 the records of a health care facility or shall require a health care facility to abstract from its own
272 records such information as is required by regulations promulgated pursuant to subsection (b).
273 The department shall compile the information in a timely manner and not later than 6 months
274 after receipt of the abstracted information from the health care facility. The department shall by
275 regulation adopt a schedule of fees which must be assessed to a health care facility for each case
276 from which information is abstracted by the department. Any person who violates this section is
277 subject to an administrative penalty established by regulation by the department.

278 (d) The department shall publish reports based upon the information obtained pursuant to
279 subsections (a), (b), and (c) and shall make other appropriate uses of the information to report
280 and assess trends in the usage of and access to health care services by patients with sickle cell
281 disease and its variants in a particular area or population, advance research and education
282 concerning sickle cell disease and its variants and improve treatment of sickle cell disease and its
283 variants and associated disorders. The reports must include, without limitation:

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

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

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

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

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

300 (g) If the commissioner or designee determines that a trend exists in the usage of and
301 access to health care services by patients with sickle cell disease and its variants in a particular
302 area or population, the commissioner or designee shall work with appropriate governmental,
303 educational and research entities to investigate the trend, advance research in the trend and
304 facilitate the treatment of sickle cell disease and its variants and associated disorders.

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

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

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

316 SCD REGISTRY AND REPORTS- DATA COLLECTION ON SCD TRAIT

317 SECTION 6. (a)(1) Notwithstanding any general or special law to the contrary, if a
318 newborn screening for hereditary disorders performed pursuant to section 270.006(A)(2)(e) of
319 chapter 105, Code of Massachusetts Regulations detects the presence of sickle cell trait, the
320 laboratory performing the screening shall notify the physician responsible for the newborn’s care

321 and shall document the patient's information in the central registry established pursuant to
322 paragraph (2) in a manner and on forms prescribed by the department of public health.

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

334 (b)(1) The commissioner of public health shall establish a central registry of patients
335 diagnosed with sickle cell trait. The information in the central registry shall be used for the
336 purposes of compiling statistical information and assisting the provision of follow-up counseling,
337 intervention, and educational services to patients and to the parents of patients who are listed in
338 the registry including, but not limited to, information concerning the availability and benefits of
339 genetic counseling performed by a genetic counselor licensed pursuant to section 253 of chapter
340 112 of the General Laws.

341 (2) The commissioner shall establish a system to notify the parents of patients who are
342 listed in the registry that follow-up consultations with a physician are recommended for children

343 diagnosed with sickle cell trait. Such notifications shall be provided: at least once when the
344 patient is in early adolescence, when the patient may begin to participate in strenuous athletic
345 activities that could result in adverse symptoms for a person with sickle cell trait; at least once
346 during later adolescence, when the patient should be made aware of the reproductive
347 implications of sickle cell trait; and at such other intervals as the commissioner may require.

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

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

358 DEVELOPMENT OF A COMPREHENSIVE SCD DISEASE QUALITY STRATEGY
359 IN MEDICAID MANAGED CARE

360 SECTION 7. (a) Notwithstanding any general or special law to the contrary, the division
361 of medical assistance shall ensure the availability of accessible, quality health care for
362 individuals with sickle cell disease who are enrolled in Medicaid managed care organizations or
363 accountable care organizations that have a contract with the division to provide services to

364 individuals enrolled under MassHealth pursuant to section 9 of chapter 118E of the General
365 Laws. Such health care shall include, but not be limited to the following:

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

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

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

371 (4) support navigating health insurance coverage and support with transportation to
372 treatment centers.

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

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

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

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

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

387 (5) in the case of an individual who is diagnosed with sick cell disease, exceptions to
388 otherwise applicable prior authorization or dispensing limits for pain medications that are
389 designed to reduce barriers for such an individual to be able to obtain the appropriate dosage and
390 amount of a pain medication in a timely manner.

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

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

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

402 (3) Enter into a contract not later than January 1, 2025, with a publicly funded university
403 to develop a sickle cell disease-focused comprehensive assessment tool or a supplement to an
404 existing comprehensive assessment tool to screen members identified with sickle cell disease for

405 comorbidities, medical history for the treatment of sickle cell disease including disease-
406 modifying medications and pain management, psychosocial history, barriers to accessing or
407 completing treatments, social supports, other care coordinators working with the member,
408 community resources being used or needed, quality of life, and personal preferences for
409 engagement with a care coordinator.

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

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

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

423 (e) The division of medical assistance shall incorporate the sickle cell disease
424 management and accountability standards into its contracts with managed care plans and
425 accountable care organizations, including financial or administrative penalties for lack of

426 performance. Contracted plan rates must be adjusted to reflect enhanced care or other provisions
427 that are shifted to the contracted plans.