



COMMONWEALTH of VIRGINIA

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December 27, 2024

MEMORANDUM

TO: The Honorable Glenn Youngkin
Governor of Virginia

The Honorable L. Louise Lucas
President Pro Tempore, Senate of Virginia

The Honorable Don Scott
Speaker of the House, Virginia House of Delegates

FROM: Karen Shelton, MD
State Health Commissioner, Virginia Department of Health

SUBJECT: 2024 Rare Disease Council Report

This report is submitted in compliance with the Code of Virginia § 32.1-73.15 (4), which states:

Submit annually by October 1 a report to the Governor and the General Assembly for publication as a report document as provided in the procedures of the Division of Legislative Automated Systems for the processing of legislative documents and reports. The annual report shall (i) describe the activities and recommendations of the Council and (ii) describe the status of funding available to the Council, including information regarding any grants applied for and received by the Council.

Should you have any questions or need additional information, please feel free to contact me at (804) 864-7002.

KS/AJ
Enclosure

Pc: The Honorable Janet V. Kelly, Secretary of Health and Human Resources

RARE DISEASE COUNCIL

REPORT TO THE GOVERNOR AND THE
GENERAL ASSEMBLY

2024



VIRGINIA DEPARTMENT OF HEALTH

PREFACE

The Rare Disease Council (Council) is tasked by the Code of Virginia (§ 32.1-73.14 through 32.1-73.17) with advising the Governor and the General Assembly on the needs of individuals with rare diseases in the Commonwealth, identifying challenges that such individuals face, funding research related to rare diseases, and funding supports for persons with rare diseases. The Council is to provide a report to the Governor and the General Assembly each year by October 1 summarizing the activities and recommendations of the Council, and the status of funding available to the Council. The Virginia Department of Health (VDH) is tasked with providing staff support to the Council and assisting the Council with preparing this document, which serves as the Council's 2024 report.

RARE DISEASE COUNCIL

Current Members of the Council as of June 1, 2024 (Gubernatorial Appointees)

Ms. Ijeoma Azubuko, individual diagnosed with a rare disease
Mr. John Feore, representative from the biopharmaceutical industry
Mr. Wes Fisher, individual diagnosed with a rare disease
Dr. Michael Friedlander, hospital administrator
Dr. Stephen Green, physician with expertise in rare diseases
Ms. Hermionne Johnson, vice chair
Mr. Gregory Josephs, representative of a rare disease patient organization
Dr. Peter Kasson, representative from an academic research institution
Dr. Tiffany Kimbrough, physician with expertise in rare diseases
Dr. Sharon Kopis, registered nurse or advanced practice registered nurse
Ms. Leslie Mehta, representative of rare disease patient organization
Dr. John Michos, representative from health plan companies
Dr. Angela Olmsted, pharmacist
Ms. Elissa Pierson, caregiver of a person with a rare disease
Dr. Stephen Rich, member of the scientific community
Ms. Elisabeth Scott, caregiver of a person with a rare disease
Ms. Gwen Traficant, chair

Ex Officio Members of the Council as of June 1, 2024

Mr. Marcus Allen, Department of Health
Dr. Samantha Hollins, Department of Education
Dr. Lisa Price Stevens, Department of Medical Assistance Services

Virginia Department of Health Staff Supporting the Council

Lauren Staley, Critical Congenital Heart Disease Program Coordinator and Rare Disease Council Coordinator, Office of Family Health Services

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EXECUTIVE SUMMARY

The Rare Disease Council (Council) is tasked by the Code of Virginia § 32.1-73.14 through 32.1-73.17 with advising the Governor and the General Assembly on the needs of individuals with rare diseases in the Commonwealth, identifying challenges that such individuals face, funding research related to rare diseases, and funding supports for persons with rare diseases. The Council is to provide a report to the Governor and the General Assembly each year by October 1 summarizing the activities and recommendations of the Council, and the status of the Rare Disease Council Fund (Fund). The Council held three quarterly public meetings from July 2023 through June 2024, for which the Virginia Department of Health (VDH) provided staff support. The quarterly meeting planned for August 17, 2023 was cancelled due to a lack of quorum. Findings and recommendations from the Council are listed below, and an update on funding is provided in the final section of this report.

FINDINGS

Based on public comments, presentations, and discussions from the Council's quarterly meetings, the Council identified several findings related to the needs of individuals with rare diseases, challenges such individuals face, and the role of the Rare Disease Council in supporting individuals with rare diseases, as follows:

1. There are several emerging resources for providers related to rare disease that aim to help increase providers' ability to diagnose and treat rare diseases. These include: a year-long rare disease clinical research program; the use of GeneClips, an app that shares genetic information on rare diseases that both clinicians and those with rare diseases can access; and the use of RareCAP, which is an online warehouse of clinical care protocols for rare disease patient care that could help support primary care providers.
2. The National Organization for Rare Disorders (NORD) publishes a state report card yearly, which focuses on nine distinct issue areas. The Commonwealth received a C or fail in three issue areas in the most recent published report card: medical nutrition, protecting patients in state regulated insurance, and telehealth. The reasoning cited was: Virginia's mandate for medical nutrition having limitations, Virginia not taking enough action to mitigate the expansion of short-term, limited-duration health plans (STLDIs), and Virginia's lack of participation in the Interstate Medical Licensure Compact (IMLC), which provides access to telehealth services across states.
3. The Council heard from several stakeholders that more timely diagnosis of Krabbe Disease would increase supportive care for those individuals who have Krabbe. While Krabbe was not recommended to be added to the Virginia newborn screening panel in 2015 and 2020, Virginia will be revisiting adding Krabbe to the state's panel, given that Krabbe was recently added to the national Recommended Uniform Screening Panel (RUSP).
4. The Council is not well known in the rare disease community yet. To be able to better provide insights to the Governor and the General Assembly regarding the needs of Virginians with rare diseases and their caregivers, the Rare Disease Council needs to

raise awareness about its work and build relationships with the rare disease community. To accomplish this, the Chair and Vice-Chair plan to conduct statewide visits in four regions across the state, beginning with two of the main hospital systems in Southwest Virginia. Information gathered will be included in the 2025 Rare Disease Annual Report. The Council also discussed the need to connect with sponsors and/or state legislators to bring awareness to the work of the Council, though a formal action plan has not been established.

RECOMMENDATIONS

The Council developed two recommendations based on public comments, presentations, and discussions from its quarterly meetings this year, as follows:

1. The Council recommends that the Governor and the General Assembly reconsider Virginia's participation in the IMLC. Participation in the IMLC would require the General Assembly to pass legislation to amend the Code of Virginia to authorize the state to join (IMLC, N.D.). The language of the compact must be consistent in each state that joins. Previous legislation to join the compact has been unsuccessful. However, Virginia is now one of only 11 states that have not joined the IMLC: as of November 2023, 39 states, Guam, and the District of Columbia have joined the IMLC (IMLC, N.D.). Virginia's participation would not only benefit Virginians but would also result in a "pass" on the NORD state report card for telehealth. VDH will consider working with the Department of Health Professions (DHP) to discuss legislative action on this topic, as joining the IMLC would require a change to their section of the Code.
2. The Council recommends that the General Assembly appropriate \$20,000 in General Funds to support the work of the Council. Specifically, the funding would be used to conduct a large-scale dissemination of a pilot rare disease survey to better understand the prevalence of rare disease in the Commonwealth and the needs of rare disease patients in Virginia. VDH will consider proposing an agency budget amendment for the next fiscal year to support this work.

INTRODUCTION

RARE DISEASE COUNCIL MANDATE

The Rare Disease Council (Council) is tasked by the Code of Virginia (§ 32.1-73.14 through 32.1-73.17) with advising the Governor and the General Assembly on the needs of individuals with rare diseases in the Commonwealth, identifying challenges that such individuals face, funding research related to rare diseases, and funding supports for persons with rare diseases. The Council is also to conduct research and consult with experts to develop policy recommendations, publish a list of publicly accessible resources relating to rare diseases on the Council's webpage, submit a report annually by October 1 to the Governor and the General Assembly, meet quarterly, and manage the Rare Disease Council Fund (Fund). See Appendix A for the full text of the legislation.

RARE DISEASE COUNCIL ACTIVITIES

The Council completed its third year of service to the Commonwealth on June 30, 2024. During this year, the Council met three times and offered public comment periods at each meeting. The quarterly meeting scheduled for August 17, 2023 was cancelled due to a lack of quorum. In 2023, the Council undertook the following major activities:

- Solicited presentations, held discussions, and invited public comments to learn more about the needs and challenges faced by individuals with rare diseases in Virginia.
- Improved its governance structure, including by updating the Council's bylaws and establishing a presentation policy to improve the Council's ability to engage in outreach efforts related to its mandates.
- Developed a pilot survey that will gather more information on rare diseases in the Commonwealth. Information to be gathered includes rare disease patient demographics; type and number of rare disease(s); knowledge and support of the rare disease(s); diagnosis and follow-up related to the rare disease(s); insurance and out-of-pocket costs; access to specialist centers; utilization of telehealth; and caregiving for rare disease patients.
- Sought policy and legal guidance so that the Council could establish the Rare Disease Fund and solicit funding to carry out the work of the Council. As specified in the Code, the Council's purpose includes funding research related to rare diseases/new treatments for rare diseases and funding supports for persons with rare diseases in the Commonwealth.
- Began to draft a Funding Governance document for the Rare Disease Fund.

A summary of this year's meetings is as follows:

8/17/2023 MEETING

The 8/17/2023 Rare Disease Council meeting was cancelled due to a lack of quorum. To continue the work of the Council between meetings, the Virginia Department of Health (VDH) developed and administered a survey to the Council in September 2023 to identify key priority topic areas for a pilot rare disease survey that the Council had expressed interested in developing.

Fifteen Council members completed the survey.

11/17/2023 MEETING

The 11/17/2023 Rare Disease Council meeting was held virtually. The Council achieved a quorum, conducted introductions, including a new Vice-Chair who was appointed since the last quarterly meeting, and voted to approve the prior meeting minutes. During this meeting, the Council received presentations from Kelly Conatser (VDH), Christen Crews (VDH), and Dr. Reiger (Children's National Hospital). The Council discussed the rare disease pilot survey that they were developing. This included discussing the use of REDCap to disseminate the survey, reviewing the key priority topic area survey data that was collected from Council members in September, and discussing potential survey questions related to each key priority topic area. The Council also learned about RareCAP, an online warehouse of clinical care protocols for rare disease patient care, which could help support primary care providers. One individual participated in public comment.

2/23/2024 MEETING

The 2/23/2024 Rare Disease Council meeting was held in-person at the Virginia Hospital and Healthcare Association. The Council achieved a quorum, conducted introductions, including a new Chair and Vice-Chair, both of whom were appointed since the last quarterly meeting, voted to approve the prior meeting minutes, and voted to adopt updated bylaws and a presentation policy, which permits the Chair, Vice Chair, and Commissioner of Health, or their designee, to submit public comments and present to both the General Assembly and other public bodies on behalf of the Council without prior approval or vote from the Council members. During this meeting, the Council discussed the progression, format, and fiscal limitations of the pilot rare disease survey, reviewed the Institutional Review Board (IRB) submission process for the survey, and reviewed a Funding Governance document that VDH drafted. No individuals participated in public comment.

5/15/2024 MEETING

The 5/15/2024 Rare Disease Council meeting was held virtually. The Council achieved a quorum and voted to approve the prior meeting minutes. During this meeting, the Council received presentations from Carolyn Sheridan from the National Organization for Rare Disorders (NORD) and Council member Gregory Josephs, and engaged in two discussions, one led by the Chair, Gwen Traficant, and the other as a group. The Council received information on their state report card from NORD, which is published yearly and focuses on nine issue areas, learned about Mr. Josephs' background and how it relates to the Council's work, and participated in discussions on the Chair and Vice-Chair's plan to conduct statewide visits to gather input on rare disease needs in Virginia and on the future initiatives and interests of the Council. No individuals participated in public comment.

REPORT OUTLINE

The remainder of this report includes a summary of topics related to the Council's work, findings, and recommendations from this year. It also includes an update on funding. Appendices

follow, including the relevant section of the Code of Virginia for the Council, acronyms used in the report, and references cited in the report.

WHAT IS A RARE DISEASE?

According to the National Institutes of Health's (NIH) Genetic and Rare Diseases Information Center (GARD), a rare disease is defined as a disease or condition that impacts less than 200,000 people in the United States (NIH GARD, 2024). Currently, there are an estimated 10,000 known rare diseases (NIH GARD, 2024) and, of those diseases in which a molecular cause is known, only about 500 have approved treatments (NIH, 2024). Per the National Organization for Rare Disorders (NORD), it is estimated that there are nearly 25-30 million Americans living with a rare disease (NORD, 2024).

Currently, there is not sufficient data to understand the prevalence of rare diseases in Virginia. This data gap is what the Council hopes to address through the dissemination of the pilot rare disease survey discussed in this report.

RARE DISEASE COUNCIL FINDINGS, REPORT ON FUNDING, AND RECOMMENDATIONS

FINDINGS

Based on public comments, presentations, and discussions from the Council’s quarterly meetings, the Council identified several findings related to the needs of individuals with rare diseases, challenges such individuals face, and the role of the Rare Disease Council in supporting individuals with rare diseases, as follows:

1. There are a number of emerging resources for providers related to rare disease that aim to help increase providers’ ability to diagnose and treat rare diseases. These include a year-long rare disease clinical research program; the use of GeneClips, an app that shares genetic information on rare diseases that both clinicians and those with rare diseases can access; and the use of RareCAP, which is an online warehouse of clinical care protocols for rare disease patient care, that could help support primary care providers.
2. The National Organization for Rare Disorders (NORD) publishes a state report card yearly, which focuses on nine distinct issue areas. The Commonwealth received a C or fail in three issue areas in the most recent published report card: medical nutrition, protecting patients in state regulated insurance, and telehealth. The reasoning was cited as Virginia’s mandate for medical nutrition having limitations, Virginia not taking enough action to mitigate the expansion of short-term, limited-duration health plans (STLDIs), and Virginia’s lack of participation in the Interstate Medical Licensure Compact (IMLC), which provides access to telehealth services across states.
3. The Council heard from several stakeholders that more timely diagnosis of Krabbe Disease would increase supportive care for those individuals who have Krabbe. While Krabbe was not recommended to be added to the Virginia newborn screening panel in 2015 and 2020, Virginia will be revisiting adding this to the state’s panel, given that

Krabbe was recently added to the national Recommended Uniform Screening Panel (RUSP).

4. The Council is not well known in the rare disease community yet. To be able to better provide insights to the Governor and the General Assembly regarding the needs of Virginians with rare diseases and their caregivers, the Rare Disease Council needs to raise awareness about its work and build relationships with the rare disease community. To accomplish this, the Chair and Vice-Chair plan to hold meetings in four regions across the state, beginning with two of the main hospital systems in Southwest Virginia. Information gathered will be included in the 2025 Rare Disease Annual Report. The Council also discussed the need to connect with sponsors and/or state legislators to bring awareness to the work of the Council, though a formal action plan has not been established.

FUNDING

The Council did not apply for or receive any gifts, grants, or donations during its third year. The Council sought guidance on several legal, policy, and financial questions it needed answered in order to establish the Rare Disease Fund and its governance. Specifically, the Council's leadership and VDH staff sought input from legal and policy contacts at VDH, the Office of the Attorney General (OAG), and the Office of the Secretary of the Commonwealth on the processes for requesting gifts and donations, applying for grants, and using funds in alignment with the legislation. VDH staff and Council leadership also conducted their own research on how to establish such a Fund. Based on this outreach and research, VDH and the Council were not able to identify any preexisting templates or guidelines for a model governance document for the Fund. VDH staff and the Council intend to continue to seek guidance on this during the next fiscal year, including from the Department of the Treasury.

While VDH and the Council began drafting a funding governance document, the Council has not yet finalized the governance document, as members and staff were hoping to acquire a preexisting template to use as a model or governance document guidelines to confirm policy and legal compliance. This temporarily halted the Council's ability to establish the Fund and carry out its tasks related to funding research and other work that would require funding. Per the Code of Virginia § 32.1-73.17, money in the Fund can be used for (i) funding research related to rare diseases and the development of new treatments for rare diseases and supports for persons with rare diseases in the Commonwealth and (ii) supporting the work of the Council. Therefore, in the absence of money in the Fund, the Council was not able to carry out tasks that required financial support.

Without funding governance and funds for the Council, the Council could not move forward with a large-scale dissemination of the Council's pilot rare disease survey. Over the past year, the Council developed a survey to learn more about the scope and impact of rare diseases in the Commonwealth, using a survey developed by the Minnesota Rare Disease Advisory Council as a reference (Bogart, K., Hemmesch, A., Barnes, E, et al., 2022). Because this would be a novel survey for better understanding rare diseases, the Council wants to ensure that the survey reaches a significant portion of the rare disease community, including those outside of the Council's networks. They therefore envision a large-scale dissemination that utilizes professionalized

distribution support and offers both online and paper survey options, versus a small-scale dissemination that relies on word of mouth and is solely internet based, to yield a more comprehensive look at rare diseases in the Commonwealth. They envision a large-scale dissemination may include the following outreach methods beyond the use of RedCAP: mailing paper surveys, providing doctor's offices with printed paper surveys and flyers with survey instructions, sending the survey via text messaging, and offering the survey at events.

Pending an IRB approval, the Council plans to disseminate a small-scale pilot rare disease survey using REDCap, until funding can be established and acquired, and they can move forward with the large-scale dissemination. A small-scale pilot survey will likely produce limited results, therefore, over the next year, the Council hopes to adopt funding governance, secure funding, and organize a large-scale dissemination of the rare disease survey.

RECOMMENDATIONS

The Council developed two formal recommendations based on public comments, presentations, and discussions from its quarterly meetings this year, as follows:

1. The Council recommends that the Governor and the General Assembly reconsider Virginia's participation in the IMLC. Participation in the IMLC would require the General Assembly to pass legislation to amend the Code of Virginia to authorize the state to join (IMLC, N.D.). The language of the compact must be consistent in each state that joins. Previous legislation to join the compact has been unsuccessful. However, Virginia is now one of only 11 states that have not joined the IMLC: as of November 2023, 39 states, Guam, and the District of Columbia have joined the IMLC (IMLC, N.D.). Virginia's participation would not only benefit Virginians but would also result in a "pass" on the NORD state report card for telehealth. VDH will consider working with the Department of Health Professions (DHP) to discuss legislative action on this topic, as joining the IMLC would require a change to their section of the Code.
2. The Council recommends that the General Assembly appropriate \$20,000 in General Funds to support the work of the Council. Specifically, the funding would be used to conduct a large-scale dissemination of the rare disease survey to better understand the prevalence of rare disease and the needs of rare disease patients in Virginia. Receiving direct general funds for this work will allow the Council to move forward with implementing work that requires funding support, while the Council continues to seek guidance on applying for grants and receiving donations for the Rare Disease Fund. VDH will consider proposing an agency budget amendment for the next fiscal year to support this work.

ARTICLE 19. RARE DISEASE COUNCIL

§ 32.1-73.14. Rare Disease Council; purpose.

There is hereby created in the executive branch of state government the Rare Disease Council (the Council) for the purpose of (i) advising the Governor and the General Assembly on the needs of individuals with rare diseases in the Commonwealth; (ii) identifying challenges that such individuals face, including delays in obtaining a diagnosis or the receipt of a misdiagnosis, shortages of medical specialists who can provide treatment, and lack of access to therapies and medication used to treat rare diseases; (iii) funding research related to rare diseases and the development of new treatments for rare diseases; and (iv) funding for supports for persons with rare diseases in the Commonwealth.

2021, Sp. Sess. I, c. [303](#).

§ 32.1-73.15. Powers and duties of the Council.

The Council shall have the power and duty to:

1. Within the first year, hold public hearings and make inquiries of and solicit comments from the public to assist the Council in understanding the scope of rare diseases in the Commonwealth and the impact of rare diseases on individuals in the Commonwealth.
2. Conduct research and consult with experts to develop policy recommendations related to:
 - a. Improving access to health care and other services for individuals with rare diseases, including access to health insurance, specialists, health care services, and other necessary services for individuals with rare diseases;
 - b. The impact of health insurance coverage, cost sharing, tiers, or other utilization management procedures on access to health care and other necessary services; and
 - c. The impact of providing coverage under the state program for medical assistance services for approved health care services and medications for rare diseases.
3. Publish a list of existing publicly accessible resources on research, diagnosis, treatment, and education relating to rare diseases on the Council's webpage.
4. Submit annually by October 1 a report to the Governor and the General Assembly for publication as a report document as provided in the procedures of the Division of Legislative Automated Systems for the processing of legislative documents and reports. The annual report shall (i) describe the activities and recommendations of the Council and (ii) describe the status of funding available to the Council, including information regarding any grants applied for and received by the Council.
5. Apply for, accept, and expend gifts, grants, and donations from public or private sources to enable the Council to better carry out its objectives.

2021, Sp. Sess. I, c. [303](#).

§ 32.1-73.16. Membership; terms; quorum; meetings; staffing.

A. The Council shall have a total membership of 21 members that shall consist of 18 nonlegislative citizen members and three ex officio members. The Governor shall appoint a chairman and vice-chairman who shall be residents of the Commonwealth and shall not be employed by any federal or state government. Nonlegislative citizen members shall be appointed by the Governor and shall include, in addition to the chairman and the vice-chairman, one representative from an academic research institution in the Commonwealth that receives any grant funding for rare disease research; one geneticist licensed and currently practicing in the Commonwealth; one registered nurse or advanced practice registered nurse licensed and currently practicing in the Commonwealth, with experience in treating rare diseases; two physicians with expertise in rare diseases who are licensed and currently practicing medicine in the Commonwealth; one hospital administrator, or his designee, from a hospital in the Commonwealth that provides care to persons diagnosed with rare diseases; two persons who are 18 years of age or older who have been diagnosed with a rare disease; two caregivers of persons with a rare disease; two representatives of rare disease patient organizations operating in the Commonwealth; one licensed pharmacist with experience with drugs used to treat rare diseases; one representative from the biopharmaceutical industry; one representative from health plan companies; and one member from the scientific community who is engaged in rare disease research, which may include a medical researcher with experience conducting research on rare diseases. The Commissioner of Health, the Director of the Department of Medical Assistance Services, and the Superintendent of Public Instruction, or their designees, shall serve ex officio with nonvoting privileges. Ex officio members of the Council shall serve terms coincident with their terms of office.

Nonlegislative citizen members of the Council shall be citizens of the Commonwealth. Appointments to fill vacancies, other than by expiration of a term, shall be for the unexpired terms. Vacancies shall be filled in the same manner as the original appointments. After the initial staggering of terms, nonlegislative citizen members shall be appointed for a term of three years.

Ex officio members of the Council shall serve terms coincident with their terms of office. Appointments to fill vacancies, other than by expiration of a term, shall be for the unexpired terms. Vacancies shall be filled in the same manner as the original appointments. After the initial staggering of terms, nonlegislative citizen members shall be appointed for a term of four years.

B. The Council shall meet quarterly and the chairman and vice-chairman shall establish a meeting schedule on an annual basis. A majority of the members shall constitute a quorum.

C. Members of the Council shall serve without compensation or reimbursement.

D. The Department of Health shall provide staff support to the Council. All agencies of the Commonwealth shall provide assistance to the Council, upon request.

2021, Sp. Sess. I, c. 303.

§ 32.1-73.17. Rare Disease Council Fund.

There is hereby created in the state treasury a special nonreverting fund to be known as the Rare Disease Council Fund, referred to in this section as "the Fund." The Fund shall be established on the books of the Comptroller. All funds appropriated for such purpose and any gifts, grants, donations, and other funds received on its behalf shall be paid into the state treasury and credited

to the Fund. Interest earned on moneys in the Fund shall remain in the Fund and be credited to it. Any moneys remaining in the Fund, including interest thereon, at the end of each fiscal year shall not revert to the general fund but shall remain in the Fund. Moneys in the Fund shall be used solely for the purpose of (i) funding research related to rare diseases and the development of new treatments for rare diseases and supports for persons with rare diseases in the Commonwealth and (ii) supporting the work of the Council. Expenditures and disbursements from the Fund shall be made by the State Treasurer on warrants issued by the Comptroller upon written request signed by the Commissioner of Health.

2021, Sp. Sess. I, c. [303](#).

APPENDIX B – ACRONYMS AND ABBREVIATIONS

The following is a list of the acronyms and abbreviations appearing throughout the report and its appendices.

IMLC - Interstate Medical Licensure Compact

IRB – Institutional Review Board

NORD – National Organization for Rare Disorders

OAG – Office of the Attorney General

OFHS – Office of Family Health Services

OFM – Office of Financial Management

RUSP - Recommended Uniform Screening Panel

STLDIs - Short-Term, Limited-Duration Health Plans

VDH – Virginia Department of Health

APPENDIX C – REFERENCES

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