DOCUMENT RESUME

ED 292 900 UD 026 064

TITLE	Sickle Cell: A Selected Resource Bibliography.
INSTITUTION	National Center for Education in Maternal and Child Health, Washington, DC.
SPONS AGENCY	Health Resources and Services Administration (DHHS/PHS), Rockville, MD. Office for Maternal and Child Health Services.
PUB DATE	Sep 86
NOTE	56p.
PUB TYPE	Reference Materials - Bibliographies (131) -- Reference Materials - Directories/Catalogs (132)
EDRS PRICE	MF01/PC03 Plus Postage.
DESCRIPTORS	Audiovisual Aids; Clinical Diagnosis; Databases; Diseases; Genetics; *Health Education; *Health Materials; Health Programs; Medical Libraries; Medical Research; Public Policy; Screening Tests; *Sickle Cell Anemia
IDENTIFIERS	Child Health Care; Health Counseling; *Maternal Health

ABSTRACT

This annotated, selective bibliography lists the following types of educational and informational material on both sickle cell disease and trait: (1) professional education materials; (2) fact sheets, pamphlets, and brochures; and (3) audiovisual material. A selected list of references is provided for the following topic areas: (1) genetic counseling; (2) overview for allied health professions; (3) pathophysiology, diagnosis, and medical management; (4) pregnancy and sickle hemoglobinopathies; (5) prenatal diagnosis; (6) psychological aspects; (7) public policy; (8) screening: ethical, legal, and social aspects; and (9) sickle cell trait. Appendices present the following information: (1) source list; (2) comprehensive sickle cell centers; (3) screening and education clinics; (4) regional medical libraries; (5) selected online data bases on the Medlars network; and (6) state genetic service coordinators. (BJV)

SICKLE CELL

A Selected Resource Bibliography

NCEMCH
National Center for Education in Maternal and Child Health
38th & R Streets, N.W.
Washington, DC 20057
(202) 625-8400

September 1986

SICKLE CELL: A Selected Bibliography was produced and published by the National Center for Education in Maternal and Child Health, 38th & R Streets, N.W., Washington, DC 20057.

The National Center is a resource center that responds to public and professional inquiries in maternal and child health, including human genetics. Established in 1982, the NCEMCH provides services under a grant from the Division of Maternal and Child Health, Department of Health and Human Services.

Printed in the United States of America

88 87 86 5 4 3 2

SICKLE CELL: A SELECTED RESOURCE BIBLIOGRAPHY

TABLE OF CONTENTS

PREFACE

Sickle Cell: A Selected Resource Bibliography lists educational and informational material on both sickle cell disease and trait. Included are sources of printed and audiovisual materials.

The bibliography is intended for health professionals, both those working in the area of sickle cell and those working in other areas who wish to know more about the topic. Information on educational materials was obtained by contacting sickle cell organizations and clinical centers throughout the country. Though some publications listed are not recent, they have been included because information therein is accurate and still current. This bibliography is not meant to be comprehensive. Inclusion in the bibliography does not imply endorsement by either the National Center for Education in Maternal and Child Health or any of its sponsors.

Selected references are arranged by subject; some are listed under more than one heading. For further information explore the National Library of Medicine's MEDLARS/MEDLINE system. Local medical center libraries frequently have access to this system. Lists of Regional Medical Libraries and of the databases available on the online networks are included at the end of the publication. The cost of services depends upon the institution performing the search. In addition, there are a number of nonmedical online databases which can provide highly pertinent information, e.g., Psychological Abstracts and Sociological Abstracts. The Regional Medical Libraries as well as many public and academic libraries have access to these systems.

We wish to thank the following for their work as consultants on the previous edition: Dorothy Blackburn-Jefferson, Ph.D., former Health Educator, Sickle Cell Disease Branch, National Heart, Lung, and Blood Institute; James E. Bowman, M.D., Professor of Pathology and Medicine, and Committee on Genetics, University of Chicago, Barbara F. James, Associate Director for Health Education and Development, Howard University Center for Sickle Cell Disease; Allan S. Noonan, M.D., Chief, Genetic Diseases Services Branch, Division of Maternal and Child Health; Sonya I. Ross, former Program Director, Association for Sickle Cell Services, Education, Research, and Treatment, Inc. (ASSERT); Ruth M. White, M.S.W., Executive Director, Sickle Cell Society, Inc.

INTRODUCTION

Sickle cell disease is unique in being the first genetic disease whose molecular and genetic etiology is understood; it has become a paradigm in the understanding of genetic disease. Its pathophysiology is well defined; its rate of morbidity and mortality has declined; its prenatal diagnosis is possible and increasingly accessible.

Because of increased awareness of the scope and impact of sickle cell disease as a public health problem, the Sickle Cell Anemia Act was passed in 1972 and resulted in the development of the National Sickle Cell Disease Program. The program brought about an increase in basic and clinical research, in education, and in quantity and quality of related services. Much has been achieved in all these areas.

Despite significant advances, the disease remains a significant health problem because of unmet needs:

- pain crises are still managed by palliative measures only;
- the clinical variability of the disease is not understood;
- there remains much misunderstanding about sickle cell on the part of the public;
- there is no definitive treatment.

Current stringent fiscal restraints have placed limitations on existing research, screening, treatment, and education programs. To help fill unmet needs for professional and public education, the National Center for Education in Maternal and Child Health has developed a selected bibliography which lists resources available nationwide.

PROFESSIONAL EDUCATION MATERIALS

	TITLE	SOURCE
1.	Advances in the Pathophysiology, Diagnosis, and Treatment of Sickle Cell Disease (1982) Scott RB [ed], 180 pp. $22.00	Alan R. Liss, Inc.

Presentation of current research in pathophysiology and applications of current knowledge in diagnosis, prenatal diagnosis, and treatment of sickle cell disease and sickle-beta thalassemia.

2.	A Bibliography: Comprehensive Sickle Cell Center Program, 1972-1980 (1980) NIH publication No. 81-1460, 87 pp.	Sickle Cell Disease Branch; National Heart, Lung, and Blood Institute

A list of references on normal and abnormal hemoglobin and erythrocytes, clinical and immunological problems in sickle cell anemia, molecular genetics of hemoglobinopathies, genetic counseling, drug development, medical management, and psychosocial aspects of sickle cell disease.

3.	Community Education Program Planning Guide: Sickle Cell Trait and Diseases [n.d.], 32 pp.	National Association for Sickle Cell Disease, Inc.

Guide for planning community educational sickle cell programs. Stresses the need for high quality of services and discusses the objectives, organization, and mechanics of such a program. Lists advantages and disadvantages of various means of presenting education and information.

4.	Consensus: Transfusion Therapy in Pregnant Sickle Cell Disease Patients (1979), 8 pp.	Office for Medical Applications of Research (NIH)

Report of a 1979 consensus development conference on the use of transfusion therapy for sickle cell disease patients who are pregnant.

PROFESSIONAL EDUCATION MATERIALS

	TITLE	SOURCE

5. Evaluation and Treatment of Patients with Sickle Cell Disease (1978), 16 pp. — Cincinnati Comprehensive Sickle Cell Center

   A highly technical manual designed to guide house staff in their evaluation and treatment of patients with sickle cell disease.

6. General Planning Guide for Comprehensive Sickle Cell Programs [n.d.], 14 pp. — National Association for Sickle Cell Disease, Inc.

   A guide for planning the overall framework of a comprehensive sickle cell program. Provides direction and means for self-evaluation.

7. Genetics, Law, and Social Policy (1977) Reilly P, 275 pp. — Harvard University Press

   An exploration of American law and social policy as it applies to modern technology in human genetics. Discusses complexity of genetic screening legislation, including problems encountered in mass screening for sickle cell trait.

8. A Guide for Sickle Cell Counseling (1979) Advisory Committee for Sickle Cell Counseling, Los Angeles County Department of Health Services, 45 pp. — March of Dimes Birth Defects Foundation, Los Angeles County Chapter

   A manual for sickle cell counselors. Defines and discusses special challenges encountered. Designed as a supplement for education programs for sickle cell counselors.

9. Guidelines for Care of Patients with Sickle Cell Disease (1978) Uy CG, Scott RB, 35 pp. — Howard University Center for Sickle Cell Disease

   Manual for physicians providing services to patients with sickle cell disease. Outlines emergency room, in-patient and clinic care, management procedures, screening, reproduction, and psychosocial and counseling services.

PROFESSIONAL EDUCATION MATERIALS

	TITLE	SOURCE
10.	Help! A Guide to Sickle Cell Disease Programs and Services: United States, Bahamas, Puerto Rico, and the Virgin Islands (1983), 158 pp.	National Association for Sickle Cell Disease, Inc.

Listing of programs organized by states, cities, and counties with comprehensive sickle cell centers; sickle cell screening and education clinics; and V.A. sickle cell programs.

11.	How to Develop A Sickle Cell Organization (1975), 20 pp.	National Association for Sickle Cell Disease, Inc.

A step-by-step guide for building a community-based sickle cell program.

12.	International Aspects of Sickle Cell Disease: Proceedings of the First International Conference on Sickle Cell Disease--A World Health Problem (1976) Scott RB [ed], 172 pp.	Howard University Center for Sickle Cell Disease

Presentations of international aspects of the history of sickle cell disease, basic and clinical research, education procedures, and socioeconomic, behavioral, and cultural aspects of the disease. Histories of sickle cell disease in East Africa, the United States, and the Mediterranean. Illustrations, graphs.

13.	Laboratory Guidelines for Community Sickle Cell Programs (1975), 25 pp.	National Association for Sickle Cell Disease, Inc.

A manual to assist community groups initiate suitable laboratory programs. Along with technical instructions for hemoglobin tests, the pamphlet indicates the information obtainable from various tests and indicates when further referral is needed.

14.	Laboratory Methods for Detecting Hemoglobinopathies (1984), 155 pp.	Centers for Disease Control

This manual provides updated information on laboratory techniques for the diagnosis of clinically important hemoglobin variants.

PROFESSIONAL EDUCATION MATERIALS

	TITLE	SOURCE
15.	Management and Therapy of Sickle Cell Disease (1984) Charache S, Lubin B, Reid CD [eds], 34 pp.	Sickle Cell Disease Branch National Heart, Lung, and Blood Institute

This publication provides information on approaches to managing sickle cell disease and utilizing current state-of-the-art treatments, especially with regard to complications of the disease.

16.	Ocular Findings in Sickle Cell Disease [n.d.] Rabb MF, Jampol LM, Goldberg MF, 20 pp.	University of Illinois Comprehensive Sickle Cell Center

Descriptions and photographs of ocular manifestation of sickle cell disease. References and glossary.

16.	Ocular Findings in Sickle Cell Disease [n.d.] Rabb MF, Jampol LM, Goldberg MF, 20 pp.	University of Illinois Comprehensive Sickle Cell Center

Descriptions and photographs of ocular manifestation of sickle cell disease. References and glossary.

17.	Perspectives on Sickle Cell Anemia (1976), 28 pp.	Cincinnati Comprehensive Sickle Cell Center

Articles on diagnosis, treatment, genetic counseling, vocational training, psychosocial factors, and social and legal aspects of mass screening. Originally published in Urban Health.

18.	A Primer on Sickle Cell Conditions in Children for Physicians (1978) Whitten CF, Reprinted from Pediatric Basics, Gerber Products Co., 3 pp.	National Association for Sickle Cell Disease, Inc.

Information on laboratory tests for screening and diagnosis, on pathophysiology, on type and frequency, health problems, and medical management of children with sickle cell anemia.

PROFESSIONAL EDUCATION MATERIALS

	TITLE	SOURCE
19.	Proceedings of the First National Sickle Cell Educational Symposium (1976), 198 pp.	Sickle Cell Disease Branch; National Heart, Lung and Blood Institute

Presentation of papers at the May 1976 conference. Several professionals from medicine, education, and social services shared their experience and perspectives on research on abnormal hemoglobin production, clinical manifestations, and treatment of sickle cell patients.

20.	Protocol for Comprehensive Management of Patients with Sickle Cell Disease (1983), 51 pp. (plus appendices)	North Carolina Department of Human Resources, Sickle Cell Syndrome Program

Protocol for comprehensive management of patients with sickle cell disease including out-patient, in-patient, and emergency room care; home, nutritional, and social work management; special concerns such as pregnancy, surgery and anesthesia, blood transfusions, and ophthalmologic evaluation.

21.	Removing Cultural and Ethnic Barriers to Health Care (1985), 267 pp. (Second printing)	National Center for Education in Maternal and Child Health

Based on a conference held at the University of North Carolina in 1979, this collection of papers focuses on barriers which prevent adequate health care delivery to all cultural and ethnic groups.

22.	Screening and Counseling For Genetic Conditions: The Ethical, Social and Legal Implications of Genetic Screening, Counseling, and Education Programs (1983) President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 122 pp. $5.00	Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402 Stock No. 040-000-00461-1

Ethical guidelines for genetic screening and counseling programs across the United States. Examines past genetic screening efforts, including sickle cell. Discusses the importance of confidentiality, autonomy, knowledge, individual well-being, and equity in quality and availability of services as they relate to genetic education, screening, and counseling programs.

PROFESSIONAL EDUCATION MATERIALS

	TITLE	SOURCE
23.	Screening for Early Diagnosis of Abnormal Hemoglobins [n.d.] Scott RB, Castro O, 10 pp.	Howard University Center for Sickle Cell Disease

Why, when, and how to screen for sickle hemoglobin, with checklist of recommendations.

24.	Screening for Inherited Hemoglobinopathies [n.d.] Bonner-Payne T, 6 pp.	Northern California Comprehensive Sickle Cell Center

Description of hemoglobin structure and function and heritability of hemoglobin types. Explains purposes and importance of testing for abnormal hemoglobins for possible treatment and of genetic counseling when a hemoglobinopathy is present. Information presented in English, Spanish, Chinese, and Tagalog. General audience.

25.	Screening for Inherited Hemoglobinopathies in the Expectant Mother [n.d.] Bonner-Payne T, 6 pp.	Northern California Comprehensive Sickle Cell Center

Description of hemoglobin's role, heritability of hemoglobin types, and the importance to mother and fetus of screening the expectant mother for the presence of abnormal hemoglobin. Information presented in English, Spanish, Chinese, and Tagalog. General audience.

26.	A Self-Instructional Unit for Sickle Cell Programmers [n.d.] Filmstrip and viewer, 36 pp.	National Association for Sickle Cell Disease, Inc.

A self-instructional booklet providing information on sickle cell anemia and trait. Designed for nonmedical personnel in sickle cell programs.

27.	Selected Bibliographies on Management of Sickle Cell Anemia, Psychosocial Aspects of Sickle Cell Anemia, and Patient Education (1982) Blackburn-Jefferson DO, 10 pp.	Sickle Cell Disease Branch; National Heart, Lung, and Blood Institute

TITLE | SOURCE

28. Sickle Cell Anemia: A Medical Review (1979) Lin-Fu JS, 26 pp. — National Center for Education in Maternal and Child Health

Reviews diagnosis and medical management of sickle cell anemia.

29. Sickle Cell Anemia: A Patient-Perceived Needs Assessment (1979) Broome M, Monroe S, 110 pp. — Sickle Cell Anemia Research and Education, Inc.

Description of a statistical survey of sickle cell anemia patients; gives expert panels' recommendations based on these data--to improve the physical and mental health of those with sickle cell anemia.

30. Sickle Cell Disease: Challenges of the Eighties (1982) Scott RB [chairman], 47 pp. Reprinted from The American Journal of Pediatric Hematology/Oncology 4(2) — Masson Publishing, USA, Inc.

Presentations from 1980 seminar. Review of medical aspects of sickle cell disease, clinical research in Africa, treatment of the disease, screening of umbilical cord blood, and vocational options for those with sickle cell trait.

31. Sickle Cell Disease: Growth and Development [n.d.] Uy Cg, Scott RB, 12 pp. — Howard University Center for Sickle Cell Disease

Gives results of a study of the effect of sickle hemoglobinopathies on the growth and development of 192 children.

32. Sickle-Cell Disease: A Handbook for the General Clinician (1982) Fleming AF [ed], 145 pp, $12.50 — Churchill Livingstone Inc.

A handbook for physicians and medical students who provide or will provide medical care to patients with sickle cell disease. Outlines history of medical and scientific understanding of this disorder, information on trait, genetics, diagnosis, clinical manifestations during childhood and adulthood, problems encountered during pregnancy, and recent advances in research and medical management.

PROFESSIONAL EDUCATION MATERIALS

	TITLE	SOURCE
33.	Sickle Cell Disease: Tell the Facts--Quell the Fables (1978) Desforges JF, Milner P, Wethers DL, Whitten CF Patient Care Productions, Darien CT, 28 pp.	National Association for Sickle Cell Disease, Inc.

A guide for understanding and treatment of sickle cell anemia. Discusses sickle cell screening, counseling, and genetics of sickle cell disease and trait. Flow charts for patient management.

34.	The Young Child and Adolescent with Sickle Cell Disease (1975) Sinnette CH, Smith JA, Smith CH [eds], 115 pp.	Harlem Hospital Sickle Cell Center

Conference proceedings of November 1974. Includes information on growth of children with the disease, guidance and vocational counseling, the adolescent, issues in screening, psychosocial impact, and counseling. Index.

	TITLE	SOURCE
1.	Alpha Thalassemia [n.d.] Bonner-Payne T, 6 pp.	Northern California Comprehensive Sickle Cell Center

Describes molecular basis, demographics, genetics, and clinical signs of the most common of the alpha thalassemias. General audience.

2.	Asi que Tengo las Caracteristicas de las Celulas Falciformes (1979) DHEW Publication No. (NIH) 78-749, 16 pp.	Sickle Cell Disease Branch; National Heart, Lung, and Blood Institute National Center for Education in Maternal and Child Health

Describes (in Spanish) sickle cell trait. For children and young adolescents. Illustrations.

3.	Beta Thalassemia [n.d.] Bonner-Payne T, 6 pp.	Northern California Comprehensive Sickle Cell Center

Describes molecular basis, genetics, demographics, and clinical signs of beta-thalassemia trait and disease (Cooley's anemia) and sickle-beta-thalassemia disease. General audience. Also available in Chinese and Tagalog.

4.	A Child with Sickle Cell Anemia in Your Class: A Guide For Teachers (1977) Scott RB, Kessler AD, 4 pp.	Howard University Center for Sickle Cell Disease

Aids teachers in understanding the possible complications of sickle cell anemia in the education of affected school-age children.

5.	A Child with Sickle Cell Disease: His Hobbies and Activities (1973) Tetrault S, 4 pp.	Howard University Center for Sickle Cell Disease

Written for parents of children with sickle cell disease suggesting guidelines to apply when helping the child select hobbies and activities. General audience.

FACT SHEETS, PAMPHLETS, AND BROCHURES

	TITLE	SOURCE
6.	Fact Sheet for Pregnant Women Who Have Sickle Cell Trait (1983) Whitten CF	National Association for Sickle Cell Disease, Inc.

Describes signs, symptoms, and prevalence of sickle cell trait. Includes information on prenatal diagnosis of sickle cell anemia. General audience.

7.	Fact Sheet on Hemoglobin C (1974) Whitten CF	National Association for Sickle Cell Disease, Inc.

Describes hemoglobin C disease and trait, including prevalence figures. General audience.

8.	Fact Sheet on Sickle Cell Trait and Anemia (1974) Whitten CF	National Association for Sickle Cell Disease, Inc.

Describes sickle cell anemia and trait, including prevalence figures. General audience.

9.	Fact Sheet on Thalassemia (1974) Whitten CF	National Association for Sickle Cell Disease, Inc.

Describes thalassemia disease and trait, and sickle thalassemia disease. General audience.

10.	Facts About Sickle Cell Trait and Sickle Cell Anemia (1975), 16 pp.	Sickle Cell Awareness Group of Cincinnati

Describes important points about the trait and anemia. Illustrated. Very young audience.

11.	The Family Connection--El Rasgo de Hemoglobina C [n.d.], 8 pp.	Harlem Hospital Sickle Cell Center

Describes (in Spanish) hemoglobin C trait, hemoglobin C-sickle cell disease and inheritance patterns. General audience.

TITLE | SOURCE

12. The Family Connection--El Rasgo de las Celulas Falciformes [n.d.], 8 pp. — Harlem Hospital Sickle Cell Center

Describes (in Spanish) the trait and its inheritance. Explains the clinical significance of the trait and the importance of knowing possible outcomes of pregnancy if one or both members of a couple are trait carriers. General audience.

13. The Family Connection: Hemoglobin C [n.d.], 8 pp. — Harlem Hospital Sickle Cell Center

Describes hemoglobin C trait, hemoglobin C-sickle cell disease, and inheritance patterns. General audience.

14. The Family Connection: Sickle Cell Trait [n.d.], 8 pp. — Harlem Hospital Sickle Cell Center

Describes the trait and its inheritance. Explains the clinical significance of sickle cell trait and the importance of knowing possible outcomes of pregnancy if one or both members of a couple are carriers. General audience.

15. The Genetics of Sickle Hemoglobin (1981), 12 pp. — University of Illinois Comprehensive Sickle Cell Center

Describes basic genetics and symptoms of sickle cell diseases. General audience with some previous exposure to basic concepts of inheritance.

16. Hemoglobin [n.d.] Bonner-Payne T, 8 pp. — Northern California Comprehensive Sickle Cell Center

Describes structure and function of hemoglobin molecule, genetics, testing procedures, and goals and methods of prenatal diagnosis of some hemoglobinopathies and thalassemias. General audience.

FACT SHEETS, PAMPHLETS, AND BROCHURES

	TITLE	SOURCE
17.	Hemoglobin C [n.d.]. Bonner-Payne T, 6 pp.	Northern California Comprehensive Sickle Cell Center

Provides a general introduction to hemoglobin disorders. Discusses hemoglobin C and the difference between hemoglobin C trait and hemoglobin C disease. Also examines sickle-hemoglobin C disease and pain crises. Also available in Spanish. General audience.

18.	Hemoglobin S [n.d.] Bonner-Payne T, 6 pp.	Northern California Comprehensive Sickle Cell Center

Explains hemoglobin disorders, with emphasis on sickle hemoglobin Also available in Spanish. General audience.

19.	Hemoglobin S and Other Common Hemoglobin Variants (1984), 14 pp.	Sickle Cell Anemia Research and Education, Inc.

This brochure provides concise and comprehensive information about hemoglobin S, hemoglobin C, and the thalassemias.

20.	Highlights of the Sickle Cell Story (1973) Whitten CF, 8 pp.	National Association for Sickle Cell Diseases, Inc.

Describes sickle cell anemia and sickle cell trait. Concentrates on the genetic aspects of the disease and the chances of parents giving birth to affected children. General audience.

21.	How to Help Your Child to "Take It In Stride": Advice for Parents of Children with Sickle Cell Anemia (1974), 25 pp.	National Association for Sickle Cell Diseases, Inc.

Aids parents in understanding the special medical and psychological aspects of a child with sickle cell disease. Additional reading list. General audience.

TITLE | SOURCE

22. Learning About Hemoglobins: AC, CC, SC (1976), 12 pp. — Boston Comprehensive Sickle Cell Center

Discusses normal hemoglobin A and abnormal types C and S. Discusses hemoglobin C trait, hemoglobin C disease, and hemoglobin SC disease. Outlines inheritance patterns. General audience.

23. Our Sickle Cell Story (1975), 8 pp. — Virginia Sickle Cell Anemia Awareness Program

Describes sickle cell anemia and sickle cell trait. For young people in elementary and middle schools. Glossary.

24. Pastoral Guidance for Families Concerning Sickle Cell Anemia and Other Hemoglobin Variants [n.d.], 4 pp. — Virginia Sickle Cell Anemia Awareness Program

Briefly discusses the role of clergy in informing couples who have sickle cell trait and hemoglobin C trait. Describes clinical manifestations of sickle cell anemia and inheritance pattern of trait and anemia. Professional audience: clergy.

25. Sickle Cell Anemia: Public Health Education Information Sheet [n.d.] — March of Dimes Birth Defects Foundation

Describes sickle cell anemia and trait, the at-risk population, and genetics. Recommends that persons who think they may be affected by sickle cell obtain accurate information from a genetics or sickle cell center. General adult audience.

26. Sickle Cell Anemia: Fact Book (1976) Scott RB, 16 pp. — Virginia Sickle Cell Anemia Awareness Program

Discusses sickle cell anemia and sickle cell trait, including diagnosis, inheritance, and counseling. Briefly discusses other hemoglobinopathies and explains the meaning of the term "gene mutation." Intended as a resource for teachers, social workers, and other nonmedical professionals.

FACT SHEETS, PAMPHLETS, AND BROCHURES

	TITLE	SOURCE
27.	Sickle Cell Anemia: What Is It? [n.d.], 16 pp.	Cincinnati Comprehensive Sickle Cell Center

Introduces sickle cell anemia and trait; describes blood cell shape and pattern of inheritance. Glossary. Secondary school audience.

28.	Sickle Cell Disease: Who's At Risk? [n.d.], 6 pp.	Howard University Center for Sickle Cell Disease

Describes testing procedures for and genetics of hemoglobinopathies. Emphasizes the importance of genetic counseling.

29.	Sickle Cell Fundamentals (1975) Bowman JE, Goldwasser E, 16 pp.	Sickle Cell Disease Branch; National Heart, Lung, and Blood Institute

Describes hemoglobin molecule, genetics of sickle cell inheritance, diagnosis, geographic distribution, and treatment. A technical and comprehensive approach. Multicolor illustrations and glossary.

30.	The Sickle Cell Story (1980), 6 pp.	Howard University Center for Sickle Cell Disease

Approaches by question and answer method: definitions, descriptions, problems, and diagnosis of sickle cell anemia and trait. Adult audience.

31.	Sickle Cell Trait and Sickle Cell Anemia (1979), 14 pp.	Boston Sickle Cell Center

Introduces in a nontechnical manner sickle cell disease and trait. Illustrated. General audience.

32.	So, I Have the Sickle Cell Trait (1972) Kaufman C, 16 pp.	National Center for Education in Maternal and Child Health

Describes sickle cell trait. Illustrated. For children and adolescents.

TITLE | SOURCE

33. Tell Me About: G6PD
[n.d.], 7 pp.
Boston Sickle Cell Center

Presents information about glucose-6-phosphate dehydrogenase deficiency. Testing procedures and medical advisories for persons with G6PD deficiency are listed.

34. Testing Your Baby for Sickle Cell Anemia and Thalassemia
Northern California Comprehensive

Discusses hemoglobin and the importance of cord-blood screening in diagnosing hemoglobin diseases and identifying carriers of an abnormal hemoglobin trait. General audience. Information presented in English, Spanish, and Chinese.

35. Viewpoints
[n.d.]
National Association for Sickle Cell Disease, Inc.

Written by the editorial board of the National Association for Sickle Cell Disease, Inc., especially for persons with sickle cell anemia and their families, to help them understand new developments in diagnosis and treatment of sickle cell anemia. General audience. Issued periodically.

36. What An Employer Should Know About the Work Potential of Persons with Sickle Cell Anemia
(1977) Duncan D, Scott RB,
5 pp.
Howard University Center for Sickle Cell Disease

Explains the etiology and clinical manifestations of sickle cell anemia and trait. Describes work potential and possible limitations of those affected with sickle cell anemia. General audience; prospective employers.

37. What Everyone Should Know About Sickle Cell (1973), 15 pp.
Channing L. Bete Co., Inc.

Describes the difference between sickle cell anemia and trait and the inheritance patterns of this hemoglobinopathy. Briefly discusses testing for trait and anemia, clinical manifestations and medical management of anemia and prenatal diagnosis. Illustrations. Adolescent and young adult audience.

FACT SHEETS, PAMPHLETS, AND BROCHURES

	TITLE	SOURCE
38.	What is Sickle Cell Anemia? [n.d.], 4 pp.	Sickle Cell Anemia Disease and Research Foundation

Describes symptoms and genetics of sickle cell anemia and trait. Also describes ethnic distribution of several other heritable disorders. General audience.

39.	What is Sickle Cell Trait? (1982), 4 pp.	Howard University Center for Sickle Cell Disease

Approaches sickle cell trait by question and answer. Illustrations. General audience.

40.	What Should We Do? Especially For Couples with Sickle Cell Trait (1981), 14 pp.	Boston Comprehensive Sickle Cell Center

Addresses the situation in which both parents have sickle cell trait, discusses reproductive options, prenatal diagnosis, and the importance of parental decision making. General audience.

41.	What's All This Talk About Sickle Cell? [n.d.], 20 pp.	Howard University Center for Sickle Cell Disease

Describes sickle cell anemia and trait, process of and reasons for sickling, clinical manifestations, prevalence and genetics. Emphasizes the difference between anemia and trait. Illustrations and diagrams. General audience.

42.	When Your Child is Ill (1974), 15 pp.	Cincinnati Comprehensive Sickle Cell Center

A helpful guide for parents in determining the degree of illness. Gives tips on when and how to care for a child at home, when to call the doctor and what should be said when the doctor is called.

43.	Where's Herbie? A Sickle Cell Story (1982), 20 pp.	Sickle Cell Anemia Research and Education, Inc.

Developed by cartoonist Morrie Turner, and designed for youth and young adults, "Where's Herbie?" presents basic information about sickle cell anemia and trait through youthful dialogue.

TITLE

SOURCE

44. Word Games and Sickle Cell Anemia [n.d.], 8 pp.

Cincinnati Comprehensive Sickle Cell Center

A collection of puzzles and word search games to test knowledge of sickle cell anemia. General audience.

45. Your Child and Sickle Cell Anemia: A Guide for Parents [n.d.], 8 pp.

Boston Sickle Cell Center

Describes sickle cell disease, sickle cell crises, and the various lifestyle changes necessary to cope with these conditions.

GENETIC COUNSELING

Duncan DE, Scott RB, Castro O (1982) A mobile unit as an adjunct to a community outreach program of education, screening and counseling for sickle cell disease, nutritional anemia, and hypertension. Journal of the National Medical Association 74(10): 969-977.

Farfel MR, Holtzman NA (1984) Education, consent, and counseling in sickle cell screening programs: Report of a survey. American Journal of Public Health 74(4): 373-375.

Ferrer TL (1975) Counseling patients with genetic abnormalities. Nursing Clinics of North America 10(2): 293-305.

Murray RF (1980) Genetic counseling in sickle cell anemia and related hemoglobinopathies. Urban Health (Nov): 35-37, 46.

Murray RF, Chamberlain N, Fletcher J, Hopkins E, Jackson R, King PA, Powledge TM (1980) Special considerations for minority participation in prenatal diagnosis. Journal of the American Medical Association 243(12): 1254-1256.

Murray RF (1984) Cultural and ethnic influences on the genetic counseling process. In: Weiss JO, Bernhardt BA, Paul NW [eds] Genetic Disorders and Birth Defects in Families and Society: Toward Interdisciplinary Understanding. March of Dimes Birth Defects Foundation, White Plains, NY, 71-74.

St. Clair L, Rosner F, James G (1978) The effectiveness of sickle cell counseling. American Family Physician 17(4): 127-130.

Whitten CF, Thomas JF, Nishiura EN (1981) Sickle cell trait counseling--evaluation of counselors and counselees. American Journal of Human Genetics 33(5): 802-816.

OVERVIEW FOR ALLIED HEALTH PROFESSIONALS

Anionwu EN (1978) Sickle cell--menace in the blood. Nursing Mirror 147: 16-19.

Anionwu EN, Beattie A (1981) Learning to cope with sickle cell disease--a parent's experience. Nursing Times (July 8): 1214-1219.

Clarke PC, Clare NR (1981) Sickle cell anaemia: a challenge for health education. Health Education Journal (London) 40(2): 50-52.

Flanagan C (1980) Home management of sickle cell anemia. Pediatric Nursing 6 (2): B-D.

Kenny CW (1980) Sickle cell disease. Nursing Times (Sept 4): 1582-1584.

McFarlane JM (1975) The child with sickle cell anemia--what his parents need to know. Nursing (May): 29-33.

McFarlane JM (1977) Sickle cell disorders. American Journal of Nursing 77: 1948-1954.

Reindorf CA (1980) Sickle cell anemia: current concepts. Pediatric Nursing (Mar/Apr): E-G.

Tetrault SM (1981) The student with sickle cell anemia. Today's Education (April/May): 52MS-57MS.

PATHOPHYSIOLOGY, DIAGNOSIS, AND MEDICAL MANAGEMENT

Alavi JV (1984) Sickle cell anemia. Pathophysiology and treatment. Medical Clinics of North America 68(3): 545-556

Aluoch JR (1984) The treatment of sickle cell disease. A historical and chronological literature review of the therapies applied since 1910. Tropical and Geographical Medicine 34(4): 1-26.

Aluoch JR (1983) Current concepts in the treatment of sickle cell disease. Tropical and Geographical Medicine 35(2): 105-110.

Bainbridge R, Higgs DR, Maude GH, Serjeant (1985) Clinical presentation of homozygous sickle cell disease. Journal of Pediatrics 106(6): 881-885.

Ballas SK, Lewis CN, Noone AM, Krasnow SH, Kamarulzaman E, Burka ER (1982) Clinical hematological and biochemical features of Hb SC disease. American Journal of Hematology 13(1): 37-51.

Bannerman RM (1979) Pathophysiology and management of the severe sickling syndromes. In: Progress in Clinical and Biological Research Volume 34, Papadatos CJ, Bartsocas CS (eds) The Management of Genetic Disorders, Alan R. Liss, Inc., New York, 369-379.

Benz EJ (1984) Molecular genetics of the sickling syndromes: evolution of new strategies for improved diagnosis. American Journal of Pediatric Hematology/Oncology 6(1): 59-66.

Buchanan GR, Smith SJ, Holtkamp CA, Fuseler JP (1983) Bacterial infection and splenic reticuloendothelial function in children with hemoglobin SC disease. Pediatrics 72(1): 93-98.

Bunn HF (1982) Sickle cell disease--advances in the 1970's and challenges in the 1980's. The American Journal of Pediatric Hematology/Oncology 4(2): 166-171.

Chang H, Ewert SM, Bookchain RM, Nagel RL (1983) Comparative analysis of fifteen anti-sickling agents. Blood 61(4): 693-704.

Charache S (1981) Treatment of sickle cell anemia. Annual Review of Medicine 32: 195-206.

Chauhan PM, Kondlapoodi P, Natta CL (1983) Pathology of sickle cell disorders. Pathology Annual 18(Pt 2): 253-276.

Davies SC, Hewitt PE (1984) Sickle cell disease. British Journal of Hospital Medicine 31(6): 440-444.

Fabian, RH, Peters BH (1984) Neurological complications of hemoglobin SC disease. Archives of Neurology 41(3): 289-292.

Gaston, MH et al (1986) Prophylaxis with oral pencillin in children with sickle cell anemia. The New England Journal of Medicine 314(25): 1593-1599.

Greenwalt TJ, Zelenski KR (1984) Transfusion support for haemoglobinopathies. Clinical Haematology 13(1): 151-165.

Hardy MJ, Ragbeer MX (1985) Homozygous HbE and HbSE in a Saudi family. Hemoglobin 9(1): 47-52.

Headings VE (1982) Sickle cell disease in childhood: strategies for early diagnosis. The American Journal of Pediatric Hematology/Oncology 4(1): 67-71.

Huisman TH (1979) Sickle cell anemia as a syndrome: a review of diagnostic features. American Journal of Hematology 6(2): 173-84.

Ley TJ et al (1982) 5-Azacytidine selectively increases gamma-globin synthesis in a patient with beta-thalassemia. The New England Journal of Medicine 307(24): 1469-1475.

Maugh TH (1981) Sickle cell (II): Many agents near trials--a better understanding of the molecular basis of sickle cell disease leads to new approaches to therapy. Science 211 (Jan. 30): 468-470.

Mears JG, Lachman HM, Labie D, Nagel RL (1983) Alpha-thalassemia is related to prolonged survival in sickle cell anemia. Blood 62(2): 286-290.

Mentzer WC, Wang WC (1980) Sickle cell disease: pathophysiology and diagnosis. Pediatric Annals 9(8): 1-10.

Mentzer WC, Wang WC (1980) Sickle cell disease: prognosis and treatment. Pediatric Annals 9(8): 11-13.

Mills ML (1985) Life-threatening complications of sickle cell disease in children. Journal of the American Medical Association 254(11): 1487-1491.

Onwubalili JK (1983) Sickle cell disease and infection. Journal of Infection 7(1): 2-20.

Rucknagel D, Ferrucci S, Whitten CF, Sarniak I, Odenheimer D (1984) Alpha-Thalassemia and HbF concentration in sickle cell anemia. Progress in Clinical and Biological Research (165): 103-120.

Samuels R, Reid J, Scott RB (1985) Characteristics of menstruation in sickle cell disease. Fertility and Sterility 43(1): 139-141.

Shurafa MS, Prasad AS, Rucknagel DL, Kan YW (1982) Long survival in sickle cell anemia. American Journal of Hematology 12(4): 357-365.

Steinberg MH (1984) The sickle hemoglobinopathies genetic analyses of common phenocopies and new molecular approaches to treatment. American Journal of Medical Science 228(4): 169-174.

Steinberg MH, Hebbel RP (1983) Clinical diversity of sickle cell anemia: genetic and cellular modulation of disease severity. American Journal of Hematology 14 (4): 405-416.

Vichinsky EP, Lubin BH (1980) Sickle cell anemia and related hemoglobinopathies. Pediatric Clinics of North America 27(2): 429-477.

Walters I, Baysinger M, Buchanan I, Dahl JA, Dorn L, Finigan G (1983) Complications of sickle cell disease. Nursing Clinics of North America 18(1): 139-184.

Warner CE (1979) Surgical management of sicklemia. Journal of the National Medical Association 71(5): 457-462.

Warth JA, Rucknagel DL (1983) The increasing complexity of sickle cell anemia. Progress in Hematology (13): 25-47.

PREGNANCY AND SICKLE HEMOGLOBINOPATHIES

Charache S, Scott J, Niebyl J, Bonds D (1980) Management of sickle cell disease in pregnant patients. Obstetrics and Gynecology 55(4): 407-410.

Cunningham FG, Pritchard JA, Mason R (1983) Pregnancy and sickle cell hemoglobinopathies: results with and without prophylactic transfusions. Obstetrics and Gynecology 62(4): 419-424.

Koshy M, Ashenhurst J (1981) Management of pregnancy in sickle cell anemia. Texas Reports on Biology and Medicine 40: 273-282.

Milner PF, Jones BR, Dobler J (1980) Outcome of pregnancy in sickle cell anemia and sickle cell-hemoglobin C disease. An analysis of 181 pregnancies in 98 patients, and a review of the literature. American Journal of Obstetrics and Gynecology 138(3): 239-245.

Miller JM, Horger EO, Key TC, Walker EM (1981) Management of sickle hemoglobinopathies in pregnant patients. American Journal of Obstetrics and Gynecology 141 (3): 237-241.

Morrison JC, Blake PG, Reed CD (1982) Therapy for the pregnant patient with sickle hemoglobinopathies: a national focus. American Journal of Obstetrics and Gynecology 144(3): 268-269.

Powars DR, Sandhu M, Niland-Weiss J, Johnson C, Bruce S, Manning PR (1986) Pregnancy in sickle cell disease. Obstetrics and Gynecology 67(2): 217-228.

PRENATAL DIAGNOSIS

Alter BP (1981) Prenatal diagnosis of haemoglobinopathies: a status report. Lancet 2 (8256): 1152-1155.

Alter BP (1984) Advances in the prenatal diagnosis of hematologic diseases. Blood 64(2): 329-340.

Anderson A (1984) Some clinical implications of recombinant DNA technology with emphasis on prenatal diagnosis of hemoglobinopathies. Clinical Biochemistry 17(2): 112-119.

Antonarkasis SE, Phillips JA, Kazazian HH (1982) Genetic diseases: diagnosis by restriction endonuclease analysis. Journal of Pediatrics 100(6): 845-56.

Boehm CD, Antonarakis SE, Phillips JA, Stetten G, Kazazian HH (1983) Prenatal diagnosis using DNA polymorphisms--report on 95 pregnancies at risk for sickle cell anemia or beta-thalassemia. The England Journal of Medicine 308(18): 1054-1058.

Boehm CD, Kazazian HH (1983) Prenatal diagnosis of hemoglobinopathies. Seminar in Perinatology 7(3): 175-83.

Chang JC, Kan YW (1982) A sensitive new prenatal test for sickle cell anemia. The New England Journal of Medicine 307(1): 30-32.

Elias S, Verp MS (1983) Prenatal diagnosis of genetic disorders. Obstetrics and Gynecology Annual 12: 79-102.

Golbus MS (1981) Antenatal diagnosis of hemoglobinopathies, hemophilia and hemolytic anemias. Clinical Obstetrics and Gynecology 24(4): 1055-1067.

Jones JR, McCormack M, Dietzel C, Tricomi V, Ramirez F (1982) Antenatal diagnosis of sickle cell disease: amniotic-fluid cell DNA analysis. Obstetrics and Gynecology 59(4): 484-489.

Kan Y, Dozy A (1978) Antenatal diagnosis of sickle cell anemia by DNA analysis of amniotic-fluid cells. Lancet 2: 910.

Kan YW, Chang JC, Dozy AM (1982) Prenatal diagnosis by DNA analysis. Birth Defects 18(7): 275-283.

Marx JL (1978) Restriction enzymes: prenatal diagnosis of genetic disease. Science 202 (Dec 8): 1068-1069.

Murray RF, Chamberlain N, Fletcher JC, Hopkins E, Jackson R, King PA, Powledge TM (1980) Special considerations for minority participation in prenatal diagnosis. Journal of the American Medical Association 243(12): 1254-1256.

Orkin SH, Little PFR, Kazazian HH, Boehm CD (1982) Improved detection of the sickle mutation by DNA analysis--application to prenatal diagnosis. The New England Journal of Medicine 307(1): 32-36.

Orkin SH (1984) Prenatal diagnosis of hemoglobin disorders by DNA analysis. Blood 63(2): 249-253.

Phillips JA (1981) Prenatal diagnosis of sickle cell anemia and beta-thalassemia by amniocentesis. Texas Reports on Biology and Medicine 40: 273-282.

Phillips JA (1983) Clinical applications of restriction endonuclease analysis. Birth Defects 19(5): 73-86.

Wong SC, Ali MA, Benzie R (1984) The intrauterine diagnosis of hemoglobin disorders. Clinical Perinatology 11(2): 283-308.

PSYCHOSOCIAL ASPECTS

Alleyne SI, Wint E, Serjeant GR (1976) Psychosocial aspects of sickle cell disease. Health and Social Work 1(4): 105-119.

Anderson LP, Rehm LP (1984) The relationship between strategies of coping and perception of pain in three chronic pain groups. Journal of Clinical Psychology 40(5): 1170-1177.

Conyard S, Krishnamurthy M, Dosik H (1980) Psychosocial aspects of sickle cell anemia in adolescents. Health and Social Work 5(1): 20-26.

Duncan D (1984) Helping families cope with sickle cell disease. In: Weiss JO, Bernhardt BA, Paul NW [eds] Genetic Disorders and Birth Defects in Families and Society: Toward Interdisciplinary Understanding. March of Dimes Birth Defects Foundation, White Plains, NY, 87-89.

Graham AV et al (1982) Care of a troubled family and their child with sickle cell anemia. Journal of Family Practice 15(1): 23-32.

Kellon DB, Beutler E (1974) Physician attitudes about sickle cell disease and sickle cell trait. Journal of the American Medical Association 227(1): 71-72.

Kumar S, Powars D, Allen J, Haywood IJ (1976) Anxiety, self-concept, and personal and social adjustments in children with sickle cell anemia. The Journal of Pediatrics 88(5): 859-863.

Leavell SR, Ford CV (1983) Psychopathology in patients with sickle cell disease. Psychosomatics 24(1): 23-37.

Masek BJ, Fentress DW, Spirito A (1984) Behavioral treatment of symptoms of childhood illness. Clinical Psychology Review 4(5): 561-70.

Mattsson A, Kim SP (1982) Blood disorders. Psychiatric Clinics of North America 5(2): 345-356.

Silber T (1983) Chronic illness in adolescents: a sociological perspective. Adolescence 18(71): 675-677.

Vavasseur J (1977) A comprehensive program for meeting psychosocial needs of sickle cell anemia patients. Journal of the National Medical Association 69(5): 335-339.

Whitten CF, Fischoff J (1974) Psychosocial effects of sickle cell disease. Archives of Internal Medicine 133(4): 681-689.

Weiss JO (1981) Psychosocial stress in genetic disorders: a guide for social workers. Social Work in Health Care 6(4): 17-31.

PUBLIC POLICY

Bowman JE (1983) Is a national program to prevent sickle cell disease possible? American Journal of Pediatric Hematology/Oncology 5(4): 367-372.

Bowman JE (1977) Genetic screening programs and public policy. Phylon 38(2): 117-142.

Gaston M, Rosse WF (1982) The cooperative study of sickle cell disease: review of study design and objectives. American Journal of Pediatric Hematology/Oncology 4(2): 197-201.

Rosner F, St. Clair L, Karayalcin G, Tatsis B (1982) A decade of experience with a sickle cell program. New York State Journal of Medicine 82(11): 1546-1554.

Scott RB (1983) Historical review of legislative and national initiatives for sickle cell disease. American Journal of Pediatric Hematology/Oncology 5(4): 346-351.

SCREENING: ETHICAL, LEGAL, AND SOCIAL ASPECTS

Bowman JE (1983) Identification and stigma in the workplace. In: Weiss JO, Bernhardt BA, Paul NW [eds] Genetic Disorders and Birth Defects in Families and Society: Toward Interdisciplinary Understanding. March of Dimes Birth Defects Foundation, White Plains, NY, 223-229.

Bowman JE (1974) Social implications of sickle cell programs. Urban Health 3 (Aug): 16-17, 32.

Bowman JE (1978) Social, legal and economic issues in sickle cell programs. In: Buckley JJ (ed) Genetics Now: Ethical Issues in Genetic Research, University Press of America, Washington, D.C. 141-171.

Calabrese EJ (1981) Genetic screening for hypersusceptibles in industry. Medical Hypotheses 7: 393-399.

Carter R (1977) Legal considerations of compulsory sickle cell screening. The Journal of Legal Medicine (March): 8AA-8FF.

Fletcher JC (1983) Ethics and trends in applied human genetics. Birth Defects 19(5) 143-58.

Fletcher JC (1981) Ethical issues in genetic screening and antenatal diagnosis. Clinical Obstetrics and Gynecology 24(4): 1151-1168.

Githens JH (1979) Sickle cell screening. Rocky Mountain Medical Journal 76(1): 21-25.

Kenen H, Schmidt RM (1978) Stigmatization of carrier status: social implications of heterozygote genetic screening programs. American Journal of Public Health 68: 1116-1120.

Miller DR (1979) Pitfalls of newborn screening for sickle cell anemia. American Journal of Diseases of Childhood 133: 1235-1236.

Murray TH (1983) Warning: Screening workers for genetic risk. The Hastings Center Report 13(1): 5-8.

Rowley PT (1984) Genetic screening: marvel or menace? Science 225: 138-144.

Schmidt RM (1974) Hemoglobinopathy screening: approaches to diagnosis, education, and counseling. American Journal of Public Health 64(8): 799-804.

Scott RB, Harrison DL (1982) Screening of the umbilical cord blood for sickle cell disease. The American Journal of Pediatric Hematology/Oncology 4(2): 202-205.

Scott RB, Castro O (1979) Screening for sickle cell hemoglobinopathies. Journal of the American Medical Association 241(11): 1145-1147.

Wright EE, Shaw MW (1981) Legal liability in genetic screening, genetic counseling, and prenatal diagnosis. Clinical Obstetrics and Gynecology 24(4): 1133-1149.

SICKLE CELL TRAIT

Benjamin GC (1983) Sickle cell trait and sickle cell anemia: a review. Military Medicine 148(9): 701-706.

Caldwell CW (1984) The sickle cell trait: a rebuttal. Military Medicine 149(3): 125-129.

Cameron BF, Smith DB, Cody B (1984) Hemoglobin S Levels in sickle cell trait individuals. American Journal of Hematology 16: 123-127.

Diggs LW (1984) The sickle cell trait in relation to the training and assignment of duties in the armed forces: I. Policies, observations, and studies. Aviation, Space, and Environmental Medicine 55(3): 180-185.

Diggs LW (1984) The sickle cell trait in relation to the training and assignment of duties in the armed forces: II. Aseptic splenic necrosis. Aviation, Space, and Environmental Medicine 55(4): 271-276.

Diggs LW (1984) The sickle cell trait in relation to the training and assignment of duties in the armed forces: III. Hyposthenuria, hematuria, sudden death, rhabdomyolysis, and acute tubula necrosis. Aviation, Space, and Environmental Medicine 55(5): 271-276.

Diggs LW (1984) The sickle cell trait in relation to the training and assignment of duties in the armed forces: IV. Consideration and recommendations. Aviation, Space, and Environmental Medicine 55(6): 487-492.

Friedman MJ, Trager W (1981) The biochemistry of resistance to malaria. Scientific American 244(3): 154-5, 158-64.

Howe EG, Kark JA, Wright DC (1983) Studying sickle cell trait in healthy army recruits: Should the research be done? Clinical Research 31(2) 119-125.

Johnson LN (1982) Sickle cell trait: an update. Journal of the National Medical Association 74(8): 751-757.

Knasel A (1982) Is sickle cell trait a health hazard? Medical problems: a brief review. The American Journal of Pediatric Hematology/Oncology 4(2): 179-181.

Long ID (1982) Sickle cell trait and aviation. Aviation, Space, and Environmental Medicine 53(10): 1021-1029.

McKenzie JM (1982) Vocational options for those with sickle cell trait. The American Journal of Pediatric Hematology/Oncology 4(2): 172-178.

Rayman RB (1979) Sickle cell trait and the aviator. Aviation, Space and Environmental Medicine 50(11): 1170-1172.

Sears DA (1978) The morbidity of sickle cel trait: a review of the literature. The American Journal of Medicine 64: 1021-1033.

Whitten CF, Thomas JF, Nishiura EN (1981) Sickle cell trait counseling--evaluation of counselors and counselees. American Journal of Human Genetics 33(5): 802-816.

AUDIOVISUAL MATERIALS

	TITLE	SOURCE
1.	A Closer Look at Sickle Cell Anemia (1979) Secondary, General audience 16 mm film; 28 min.; color	Producer: Golden Door Productions Distributor: Children's Hospital Medical Center of Northern California

Discusses sickle cell anemia and sickle cell trait, inheritance, ethical issues in genetic counseling and screening, and sickle cell crises. The need for counseling in conjunction with screening programs is stressed and nondirective counseling is encouraged.

2.	The Chronically Ill Student - On the Road to Learning (1984) Professional/General audience 1/2" vidocassette; 26 min.; color	Producer/ Distributor: Sickle Cell Awareness Group of Greater Cincinnati

A thorough and sensitive presentation of the needs of the chronically ill student. Contains valuable information for parents, educators and health professionals.

3.	Genetic Screening: The Ultimate Preventive Medicine (1980) General audience 3/4" videocassette; 59 min.; color	Producer: KCTS-TV, Seattle Distributor: PBS Video

Explores ethical questions emerging as a result of the availability of prenatal diagnosis for various genetic diseases. Differences between screening programs, sickle cell anemia, Tay Sachs, and PKU are described as well as the ways in which these differences influence the success of the programs.

4.	Haemoglobinopathies S,C,D,E (1979) Professional/General audience 55 slides and audiocassette; 28 min.; color	Producer/ Distributor: Toronto Institute of Medical Technology

Outlines molecular basis of hemoglobinopathies S,C,D, and E. Illustrates geographic origins, diagnostic procedures, discusses clinical manifestations of these disorders and prenatal diagnosis of sickle cell anemia.

AUDIOVISUAL MATERIALS

	TITLE	SOURCE

leave blank for page 34

5. Living with Hope (1983)
Secondary, General audience
3/4" videocassette; 21 min.; color
Producer/Distributor: Sickle Cell Anemia Research and Education Inc.

Discusses sickle cell anemia and sickle cell trait through interviews with parents, patients, and health care professionals. Also discusses the history and diagnosis of sickle cell anemia and research presently being conducted.

6. Sickle Cell: Anemia or Trait, The Problem Explained (1978)
Secondary, General audience
3/4" videocassette; 13 min.; color
Producer: Virginia Sickle Cell Awareness Program
Distributor: Medical College of Virginia

Explains the difference between sickle cell anemia and sickle cell trait, that trait cannot become anemia, that these are genetic, not infectious conditions. Discusses options for couples in which both members are trait carriers.

7. Sickle Cell Anemia
3/4" videocassette, 16mm film
22 min.; color
Producer: Canadian Broadcasting Company
Distributor: Filmakers Library, Inc.

Discusses sickle cell anemia on a scientific and human level. Features interviews with a family in which there are three affected children.

8. Sickle Cell Anemia (1977)
Secondary, General audience
3/4" videocassette, 29 min.; color
Producer: KERA-TV Dallas
Distributor: PBS Video

Dr. Daniel Foster and guest, Dr. Helen M. Ranney--professor and head of the Department of Internal Medicine at the University of California at San Diego, discuss various aspects of sickle cell anemia.

AUDIOVISUAL MATERIALS

	TITLE	SOURCE	
9.	Sickle Cell Anemia: A Genetic Disease (1979) Secondary, General audience 16 mm film; 15 min.; color	Producer: Distributor:	Golden Door Productions Children's Hospital Medical Center of Northern California

Discusses sickle cell anemia and sickle cell trait, including patterns of inheritance, structure and function of normal red blood cells and hemoglobin. Examines amino acid substitution in beta globin chains and sickle cell hemoglobin. Discusses research and management of sickle cell anemia and counseling of persons with sickle cell trait.

10.	Sickle Cell Anemia: The Facts (1978) 3/4" videocassette; 9 min.; color	Producer: Distributor:	Virginia Sickle Cell Awareness Program Medical College of Virginia

Three individuals affected with sickle cell disease describe physical psychological, social, and financial aspects of the disease.

11.	Sickle Cell Disease I - Basic Aspects (1981) Professional audience slide/sound; 50 min.; color	Producer/ Distributor:	Medcom, Inc.

Highly technical discussion of sickle hemoglobinopathies including terminology, geographic distribution and prevalence, molecular aspects of hemoglobin structure and function, erythrostasis, oxygen transport, hematologic and erythrokinetic aspects, and genetics.

12.	Sickle Cell Disease II - Clinical Aspects (1981) Professional audience slide/sound; 78 min; color	Producer/ Distributor:	Medcom, Inc.

Detailed description of sickle hemoglobinopathies including pathogenesis, many and varied clinical features (e.g., pain crisis, anemic crisis, bone infarct, peptic ulcer, cholelithiasis, ocular manifestations), diagnostic procedures, and medical management. Stresses importance of distinguishing between pain crises of sickle cell and related or unrelated life-threatening conditions.

AUDIOVISUAL MATERIALS

	TITLE	SOURCE	
13.	Sickle Cell Fundamentals, Part I- The Molecular Biology of Hemoglobins (1978) Professional/ General audience 16mm film; 15 min.; color; brochure	Producer: Distributor:	University of Chicago Sickle Cell Disease Branch; National Heart, Lung, and Blood Institute

The molecular basis for sickle cell anemia is described. Using animation, depicts the deoxygenated and oxygenated forms of the hemoglobin molecule and explains in lay terms how water-soluble and - insoluble amino acids interact with cellular constituents.

14.	Sickle Cell Fundamentals, Part II- Inheritance of Hemoglobins (1978) General, Professional audience 16mm film; 15 min.; color; brochure	Producer: Distributor:	University of Chicago Sickle Cell Disease Branch; National Heart, Lung, and Blood Institute

Describe how sickle cell anemia is inherited and illustrates the probability of a couple having children with the disease or the trait. Discusses the possible improved resistance to malaria of those with the trait. Reviews briefly several other hemoglobin diseases that can cause anemia. Explains the use of electrophoresis as a tool for the diagnosis of sickle cell.

15.	The Sickle Cell Story (1977) Secondary, General audience 16mm film; 16 min.; color	Producer: Distributor:	Howard University Center for Sickle Cell Disease Milner-Fenwick, Inc.

Describes the historical background and physiology of sickle cell anemia and the difference between sickle cell disease and sickle cell trait. Features a young couple coming to terms with their carrier status and their experience with genetic counseling.

16.	Sickle Cell Trait Counseling [n.d.] Professional audience 16mm film; 30 min.; color	Producer/ Distributor:	Wayne State University

Designed as a training film for sickle cell trait counselors or other health professionals. Demonstrates several psychosocial problems that may arise in individuals with sickle cell anemia and in families with an affected child. Each episode is followed by blank spots to allow for audience discussion.

AUDIOVISUAL MATERIALS

	TITLE	SOURCE	
17.	The Sickle Shaped Cell (1978) Primary, Secondary audience 16mm film; 12 min.; color	Producer: Distributor:	Golden Door Productions Children's Hospital Medical Center of Northern California

Uses animation to explore modes of transmission of recessive disorders. Mentions structure of red blood cells.

18.	Where's Herbie (1985) Primary, Secondary Audience 1/2" or 3/4" videocassette; 14 min., 30 sec.; color	Producer/ Distributor:	Sickle Cell Anemia Research and Education, Inc.

Developed by cartoonist Morrie Turner, and designed for youth and adults, "Where's Herbie?" presents basic information about sickle cell anemia and trait through youthful dialogue.

APPENDIX A

Source List

1. Alan R. Liss, Inc.
150 Fifth Avenue
New York, NY 10011
(212) 741-2515

2. Boston Sickle Cell Center
818 Harrison Avenue
Boston, MA 02118
(617) 424-5727

3. Centers for Disease Control
Center for Infectious Diseases
Division of Host Factors
Atlanta, GA 30333
(404) 329-3925

4. Channing L. Bete Company, Inc.
200 State Road
South Deerfield, MA 01373
(413) 665-7611

5. Children's Hospital Medical Center
of Northern California
Sickle Cell Films Department
51st and Grove Street
Oakland, CA 94609
(415) 654-5600

6. Churchill Livingstone Inc.
1560 Broadway
New York, NY 10036
(212) 819-5400

7. Cincinnati Comprehensive Sickle
Cell Center
Children's Hospital Research Foundation
Elland and Bethesda Avenues
Cincinnati, OH 45229
(513) 559-4541

8. Filmakers Library, Inc.
133 East 58th Street
New York, NY 10022
(212) 355-6545

9. Golden Door Productions
Tenth and Parker
Berkeley, CA 94710
(415) 849-3571

10. Harlem Hospital Sickle Cell Center
506 Lenox Avenue
New York, NY 10037
(212) 491-8076

11. Harvard University Press
79 Garden Street
Cambridge, MA 02138
(617) 495-2600

12. Howard University Center for
Sickle Cell Disease
College of Medicine
2121 Georgia Avenue, N.W.
Washington, DC 20059
(202) 636-7930

13. King-Drew Sickle Cell
Center
12012 Compton Avenue
Suite 1-212 (I and R Building)
Los Angeles, CA 90059
(213) 603-3166

14. March of Dimes Birth Defects
Foundation
1275 Mamaroneck Avenue
White Plains, NY 10605
(914) 428-7100

15. March of Dimes Birth Defects
Foundation
Los Angeles County Chapter
1111 South Central Avenue
Glendale, CA 91204
(818) 349-1080

16. Masson Publishing, USA, Inc.
133 East 58th Street
New York, NY
(516) 349-1080

17. Medcom, Inc.
12601 Industry St.
Garden Grove, CA 92641
(800) 223-2505

18. Milner-Fenwick, Inc.
2125 Greenspring Drive
Timonium, MD 21093
(800) 638-8652
(301) 252-1700

19. National Association for Sickle Cell Disease, Inc.
4221 Wilshire Boulevard
Suite 360
Los Angeles, CA 90010-3503
(213) 936-7205
(800) 421-8453

20. North Carolina Department of Human Resources
Division of Health Services
Maternal and Child Care Section
Developmental Disabilities Branch
Genetic Health Care Unit
Raleigh, NC 27602
(919) 733-4261

Sickle Cell Center
San Francisco General Hospital
1001 Potrero Avenue, Rm. 6B9
San Francisco, CA 94110
(415) 821-5169

22. Office for Medical Applications of Research
National Institutes of Health
Building 1, Room 216
(301) 496-1143

23. National Center for Education in Maternal and Child Health
38th and R Streets, N.W.
Washington, DC 20057
(202) 625-8400

24. PBS Video
1320 Braddock Place
Alexandria, VA 22314-1698
(703) 739-5000
(800) 424-7964

25. PSG Publishing Company, Inc.
545 Great Road
Littleton, MA 01460
(617) 486-8971

26. Sickle Cell Anemia Research and Education, Inc.
(S.C.A.R.E.)
330 41st Street
Oakland, CA 94609
(415) 547-6965

27. Sickle Cell Awareness Group of Greater Cincinnati, Inc.
3595 Washington Avenue
Cincinnati, OH 45229
(513) 281-4450

28. Sickle Cell Disease Branch
National Heart, Lung, and Blood Institute
National Institutes of Health
Federal Office Building
Bethesda, MD 20205
(301) 496-6931

29. Sickle Cell Disease Research
1334 Haight Street
San Francisco, CA 95117
(415) 626-5834

30. Sickle Cell Society, Inc.
Medical Center East Building
Suite 742
211 North Whitfield Street
Pittsburgh, PA 15206-9990
(412) 441-6116

31. Toronto Institute of Medical Technology
Media and Instructional Services
222 Patrick Street
Toronto, Ontario M5T IV4
(416) 596-3101

32. University of Illinois Medical
Center
Comprehensive Sickle Cell Center
1919 West and Taylor Street
Chicago, IL 60612
(312) 996-7013

33. Virginia Sickle Cell Awareness Program
Medical College of Virginia
Richmond, VA 23298
(804) 786-0503

34. Comprehensive Sickle Cell Center
Wayne State University
Children's Hospital of Michigan
3901 Beaubien Boulevard
Detroit, MI 48201
(313) 577-1546

Comprehensive Sickle Cell Centers - September 1986

CALIFORNIA

Comprehensive Sickle Cell Center
University of Southern California
School of Medicine
2025 Zonal Avenue
Los Angeles, CA 90033
L. Julian Haywood, M.D., Director
(213) 226-7116

Comprehensive Sickle Cell Center
University of California
San Francisco General Hospital
1001 Potrero Avenue
Building 20, Room 2108
San Francisco, CA 94110
William C. Mentzer, M.D., Director
(415) 821-5169

DISTRICT OF COLUMBIA

Comprehensive Sickle Cell Center
Howard University College of
Medicine
2121 Georgia Avenue, NW
Washington, DC 20059
Roland B. Scott, M.D., Director
(202) 636-7930

GEORGIA

Comprehensive Sickle Cell Center
Medical College of Georgia
Department of Cell and Molecular
Biology
Augusta, GA 30912
Titus H.J. Huisman, Ph.D., D.Sc.
Director
(404) 828-3091

ILLINOIS

Comprehensive Sickle Cell Center
University of Illinois Medical
Center
1919 West Taylor Street
Chicago, IL 60612
Maurice F. Rabb, M.D., Director
(312) 996-7013

MASSACHUSETTS

Comprehensive Sickle Cell Center
Boston City Hospital
818 Harrison Avenue, FGH-2
Boston, MA 02118
Lillian E.C. McMahon, M.D., Director
(617) 424-5727

MICHIGAN

Comprehensive Sickle Cell Center
Wayne State University School of
Medicine
Children's Hospital of Michigan
3901 Beaubien Boulevard
Detroit, MI 48201
Charles F. Whitten, M.D., Director
(313) 577-1546

NEW YORK

Comprehensive Sickle Cell Center
College of Physicians & Surgeons
Columbia University
630 West 168th Street
New York, NY 10032
Sergio Piomelli, M.D., Director
(212) 305-5998

NORTH CAROLINA

Comprehensive Sickle Cell Center
Duke University Medical Center
Box 3934
Morriss Building
Durham, NC 27710
Wendell F. Ross, M.D., Director
(919) 684-3724

OHIO

Comprehensive Sickle Cell Center
Children's Hospital Research
Foundation
Elland and Bethesda Avenues
Cincinnati, OH 45229
Donald Rucknagel, M.D., Director
(513) 559-4543

APPENDIX C

Sickle Cell Screening and Education Clinics - September 1986

ALABAMA

North Center Sickle Cell
Foundation
Jefferson County Sickle Cell Clinic
1025 South 18th Street, Ground Floor
Birmingham, AL 35205
Sharon B. Lewis, M.P.H.,
Executive Director
(205) 933-8704

GEORGIA

Sickle Cell Foundation of Georgia, Inc.
2391 Benjamin E. Mays Drive, S.W.
Atlanta, GA 30311
D. Jean Brannan, Project Director
(404) 755-1641

INDIANA

Martin Center, Inc.
Sickle Cell Program
3549 North College Avenue
Indianapolis, IN 46205
Sister Jane Schilling,
Project Director
(317) 927-5150

MARYLAND

Association for Sickle Cell Services--
Education, Research and Treatment, Inc.
(ASSERT)
Lower Park Heights
Multipurpose Center, Room 204
3039 Reisterstown Road
Baltimore, MD 21215
Carolyn Boston, Project Director
(301) 578-1800

MISSOURI

Metro Community Health Center, Inc.
Genetic Disease Program
2730 N. Grand Boulevard
St. Louis, MO 63106
Ronald G. Hill, Project Director
(314) 531-0113

NEW YORK

Long Island Jewish-Hillside
Medical Center Sickle Cell Program
Queens Hospital Center Affiliation
8268 - 164th Street
Queens, NY 11432
Wanda Jones-Robinson,
Project Director
(212) 990-3291

Long Island Sickle Cell Project, Inc.
510 South Franklin Street
Hempstead, NY 11550
Mary Little, Executive Director
(516) 538-6060

NORTH CAROLINA

Association for Sickle Cell Disease
for Charlotte-Metroline, Inc.
Medical Center, Suite #320
915 South Independence Boulevard
Charlotte, NC 28202
Peggy H. Beckwith, Executive
Director and Project Administrator
(704) 332-4184

Operation Sickle Cell, Inc.
513 Murchison Road
Fayetteville, NC 28301
Mary E. McAllister,
Project Director
(919) 483-0514

OHIO

The American Sickle Cell Anemia Association
10300 Carnegie Avenue
Cleveland, OH 44106
William True, Project Director
(216) 229-8600

ECCO Family Health Center
1166 East Main Street
Columbus, OH 43205
Gwendolyn Macon, Project Director
(614) 253-0861

Drew Sickle Cell and Other Genetic Diseases
184 Salem Avenue, Suite 227
Dayton, OH 45406-5804
Al Thompson, Project Director
(513) 223-4612

Grace B. Myers Clinic
426 Lincoln Park Circle
Springfield, OH 45505
Gwendolyn Bellamy, Executive Director
(513) 325-0464

Ohio Sickle Cell and Health Association (OSCHA)
1393 East Broad Street
Columbus, OH 43205
Judith Watkins, Contact Person
(614) 252-1090

PENNSYLVANIA

Sickle Cell Society, Inc.
Medical Center East, Suite 170
211 North Whitfield Street
Pittsburgh, PA 15206
Ruth M. White, M.S.W., Project Director
(412) 441-6116

SOUTH CAROLINA

Committee on Better Racial Assurance
Sickle Cell Program
PO Box 2154 - 54 Morris Street
Charleston, SC 29403
Bill Saunders, Project Director
(803) 792-3711

TENNESSEE

MeHarry Medical College
Sickle Cell Center
1005 Dr. D.B. Todd Jr. Boulevard
Nashville, TN 37208
Ernest Turner, M.D.
Project Administrator
(615) 327-6763

TEXAS

Sickle Cell Anemia Foundation of Dallas
401 Wynnewood Professional Building
Suite 205
Dallas, TX 75224
Arnold Hider, M.S.W., Executive Director
(214) 942-1262

Sickle Cell Disease Foundation of Texas, Inc.
2410 Hamilton Street, Suite 210
Houston, TX 77004
Darnelle' D. Pinkard, M.S.W., Executive Director
(713) 651-8071

VIRGINIA

Virginia Sickle Cell Anemia Awareness Program
Medical College of Virginia
MCV Station Box 158
1215 East Marshall Street
Richmond, VA 23298
Project Director
(805) 786-0503

NOTE: The listing of screening and education clinics is an update of information in the 1983 edition of this bibliography. For more information about sickle cell clinics in your area, contact your Public Health Office or State Genetic Service Coordinator.

APPENDIX D

Regional Medical Libraries

Seven Regional Medical Libraries, each responsible for a geographic area, coordinate NLM's online search services in the United States. These libraries also handle requests for health literature not available locally, and pass on to the NLM requests they cannot fill. To find out the nearest online center, or how your institution can become a center, write to the Regional Medical Library for your area.

Region I

Greater Northeastern Regional Medical Library Program
(CT, DE, MA, ME, NH, NJ, NY, PA, RI, VT, and Puerto Rico)
The New York Academy of Medicine
2 East 103rd Street (212) 876-8763
New York, NY 10029

Region II

Southeastern/Atlantic Regional Medical Library Services (STARS)
(AL, DC, FL, GA, MD, MS, NC, SC, TN, VA, WV and the Virgin Islands)
University of Maryland
Health Sciences Library (301) 528-2855
111 South Greene Street (800) 638-6093 outside MD
Baltimore, MD 21201

Region III

Greater Midwest Regional Medical Library Network
(IA, IL, IN, KY, MI, MN, ND, OH, SD, WI)
University of Illinois at Chicago
Library of the Health Sciences (312) 996-2464
P.O. Box 7509
Health Sciences Center
Chicago, IL 60680

Region IV

Midcontinental Regional Medical Library Program (MCRML)
(CO, KS, MO, NE, UT, WY)
University of Nebraska (402) 559-4326
Medical Center Library (800) MED-RML4
42nd and Dewey Avenue
Omaha, NE 68105-1065

Region V

South Central Regional Medical Library Program (TALON)
(AR, LA, NM, OK, TX)
University of Texas (214) 688-2085
Health Science Center at Dallas
5323 Harry Hines Boulevard
Dallas, TX 75235

Region VI — Pacific Northwest Regional Health Sciences Library Service (PNRHSLS)
(AK, ID, MT, OR, WA)
Health Sciences Library (206) 543-8262
University of Washington
Seattle, WA 98195

Region VII — Pacific Southwest Regional Medical Library Service (PSRMLS)
(AZ, CA, HI, NV, and U.S. Territories in the Pacific Basin)
UCLA Biomedical Library (213) 825-1200
Center for the Health Sciences
Los Angeles, CA 90024

APPENDIX E

Selected Databases Available On The Medlars Network

AVLINE (Audiovisuals Online) contains citations to over 14,000 audiovisual teaching packages covering a wide range of subject areas in medicine, dentistry, nursing, allied health, and other disciplines. In some cases, descriptive review information such as rating, audience levels, instructional design, specialties, and abstracts is included. Procurement information on titles is provided.

BIOETHICSLINE contains bibliographic citations to documents which discuss ethical questions arising in health care or biomedical research. It is a comprehensive, cross-disciplinary collection of references to both print and nonprint materials. Among the publication types included in the database are journal and newpaper articles, monographs, analytics, court decisions, and audiovisual materials. The database contains over 19,000 citations from 1973 to date. Citations in BIOETHICSLINE appear also in the Bibliography of Bioethics, an annual publication of the Center for Bioethics, Kennedy Institute of Ethics, Georgetown University.

CATLINE (Catalog Online) contains about 600,000 references to books and serials catalogued at NLM. CATLINE gives medical libraries in the network immediate access to authoritative cataloging information and thus reduces the need for these libraries to do their own original cataloging. Libraries also find this database a useful source of information for ordering books and journals and for providing reference and interlibrary loan services.

DIRLINE (Directory of Information Resources Online) contains information on over 15,000 resource centers and can be used as a referral service to locate information not readily obtainable from the bibliographic or factual databases. Included in each record is the organization name, address, scope of coverage, and types of services provided. The file is updated quarterly.

MEDLINE contains approximately 800,000 references to biomedical journal articles published in the current and preceding three years. An English abstract, if published with the article, is included. The articles are from 3200 journals published in the United States and in foreign countries. Coverage of previous periods (back to 1966) is provided by backfiles totaling some 5,000,000 references and searchable online.

MEDLINE can also be used to update a search periodically. The search formulation is stored in the computer and each month, when new references are added to the database, the search is processed automatically and the results mailed from NLM.

POPLINE (Population Information Online) is a bibliographic database citing the literature in the areas of family planning, fertility control, population and reproduction. The POPLINE file contains citations and abstracts to a variety of materials including journal articles, monographs, technical reports, and unpublished works. POPLINE currently contains approximately 133,000 citations. The majority of the items were published from 1970 to the present, but there are selected citations dating back to 1886. The database increases by about 10,000 citations annually and is updated monthly.

SERLINE (Serials Online) contains bibliographic information for about 60,000 serial titles, including all journals which are on order or cataloged for the NLM collection. For many of these, SERLINE has locator information for the user to determine which United States medical libraries own a particular journal. SERLINE is used by librarians to obtain information needed to order journals and to refer interlibrary loan requests.

TOXLINE (Toxicology Information Online) is a bibliographic database of over 1.7 million references covering the pharmacological, biochemical, physiological, environmental, and toxicological effects of drugs and other chemicals. Almost all references in TOXLINE have abstracts and/or indexing terms and Chemical Abstracts Service (CAS) Registry Numbers.

APPENDIX F

State Genetic Service Coordinators

ALABAMA

Wayne H. Finley, M.D., Ph.D.
State Genetic Project Director
University of Alabama at Birmingham
University Station
Birmingham, AL 35294
(205) 934-4973

ALASKA

David A. Spence, M.D., M.P.H.
Chief, Section of Family Health
Alaska Department of Health
& Social Services
Division of Public Health
Health and Welfare Building
P.O. Box H-06B
Juneau, AK 99811
(907) 465-3100

ARIZONA

Frederick Hecht, M.D., Director
Southwest Biomedical Research Institute
6401 East Thomas Road
Scottsdale, AZ 85251
(602) 945-4363

ARKANSAS

Becky Butler, M.S.W.
Genetics Program Coordinator
Department of Pediatrics/512 B
University of Arkansas Medical
Sciences Campus
4301 West Markham
Little Rock, AR 72205
(501) 661-5994

CALIFORNIA

George C. Cunningham, M.D.
Chief, Genetic Disease Branch
Department of Health Services
2151 Berkeley Way, Annex 4
Berkeley, CA 94704
(415) 540-2534

COLORADO

Robert S. McCurdy, M.D., M.P.H.
Director of Medical Affairs and
Special Programs
Department of Health
4210 East 11th Avenue
Denver, CO 80220
(303) 331-8373

CONNECTICUT

Vijaya V. Bapat, M.D.
Chief, Maternal and Child
Health Section
Department of Health Services
150 Washington Street
Hartford, CT 06106
(203) 566-5601

DELAWARE

Barbara Jarrell Krausz, B.S.
Genetic Services and Newborn
Screening Manager
P.O. Box 637
Dover, DE 19903
(302) 736-4786

DISTRICT OF COLUMBIA

Jill F. Shuger, Sc.M.
Genetics Program Coordinator
Department of Human Services
Commission of Public Health
Bureau of Maternal and Child Health
1875 Connecticut Avenue, N.W.
Room 804-B
Washington, DC 20009
(202) 673-6697

FLORIDA

Mittie Moffett, R.N., M.S.
Program Administrator
Children's Medical Services
Regional Genetics Program
1317 Winewood Boulevard
Tallahassee, FL 32301
(904) 488-6005

GEORGIA

Mary S. Harris, Ph.D.
Genetics Program Director
Community Health Section
Department of Human Resources
878 Peachtree Street, N.E.
Room 109
Atlanta, GA 30309
(404) 894-5122

HAWAII

Janet Huff, R.N., M.P.H.
Department of Health
Crippled Children's Services Branch
741 Sunset Avenue
Honolulu, HI 96816
(808) 732-3197

IDAHO

Mary Jane Webb
Genetic Services Program Manager
Idaho Department of Health
& Welfare
Bureau of Laboratories
2220 Old Penitentiary Road
Boise, ID 83712
(208) 334-2235

ILLINOIS

Sydney Kling, R.N.
Administrator
Genetic Diseases Program
Division of Family Health
Illinois Department of Public Health
535 West Jefferson Street
Springfield, IL 62761
(217) 785-4522

INDIANA

F. John Meaney, Ph.D.
Chief, Genetic Diseases Section
Maternal & Child Health Division
State Board of Health
1330 West Michigan Street
Box 1964
Indianapolis, IN 46206-1964
(317) 633-0805

IOWA

Roger R. Chapman, M.S.W.
Director
Birth Defects Institute, Division
of Maternal and Child Health
Department of Health
Lucas State Office Building
Des Moines, IA 50319
(515) 281-6646

KANSAS

Carolyn K. Domingo, R.N., M.S.
Genetic Services Coordinator
Crippled & Chronically Ill
Children's Program
Department of Health and
Environment
Forbes Field #740
Topeka, KS 66620
(913) 862-9360 Ext. 400

KENTUCKY

John Webb
Genetic Program Coordinator
Department for Health Services
Division of Maternal and Child Health
275 East Main Street
Frankfort, KY 40621
(502) 564-4430

LOUISIANA

Charles Myers, Administrator
Genetic Diseases Program
Office of Preventive and Public
Health Services
Department of Health and Human
Resources
325 Loyola Avenue, Room 613
New Orleans, LA 70112
(504) 568-5075

MAINE

Mollie W. Jenckes, M.H.Sc.
Director, Genetics, Prenatal Care,
and Injury Control
Department of Human Services
Bureau of Health
Division of Maternal and Child Health
State House, Station 11
Augusta, ME 04333
(207) 289-3311

MARYLAND

Susan R. Panny, M.D., Chief
Division of Hereditary Disorders
Maryland Department of Health and
Mental Hygiene
P.O. Box 13528
201 West Preston Street
Baltimore, MD 21201
(301) 225-6730

MASSACHUSETTS

Sharon E. Reid, M.S., Director
Genetics Program
Massachusetts Department of
Public Health
Division of Family Health Services
150 Tremont Street
Boston, MA 02111
(617) 727-0944

MICHIGAN

William I. Young, Ph.D.
Genetics Program Coordinator
Michigan Department of
Public Health
3500 North Logan Street
P.O. Box 30035
Lansing, MI 48909
(517) 373-0657

MINNESOTA

Lee E. Schacht, Ph.D.
Supervisor, Human Genetics Unit
Minnesota Department of Health
717 Delaware, S.E.
Minneapolis, MN 55446
(612) 623-5269

MISSISSIPPI

Daniel R. Bender, Director
Mississippi Genetic Screening Program
Mississippi Department of Health
P.O. Box 1700
Jackson, MS 39215-1700
(601) 982-6571

MISSOURI

N. Aurita Prince, M.Ed.
Program Coordinator
Missouri Genetic Disease Program
Missouri Department of Health
P.O. Box 570
1730 East Elm Street
Jefferson City, MO 65102
(314) 751-8157

MONTANA

John M. Opitz, M.D.
Chairman, Department of Medical Genetics
Shodair Children's Hospital
840 Helena Avenue
P.O. Box 5539
Helena, MT 59601
(406) 442-1980

NEBRASKA

J. Douglas Campbell
Director, Bureau of Medical Services and Grants
Birth Defects Prevention Program
Nebraska Department of Health
301 Centennial Mall South
P.O. Box 95007
Lincoln, NE 68509
(402) 471-2647

NEVADA

Richard C. Bentinck, M.D., Chief
Bureau of Community Health Services
Nevada Division of Health
505 East King Street, Room 205
Carson City, NV 89710
(702) 885-4880

NEW HAMPSHIRE

Carol L. Struckmeyer, M.S.
Genetic Services Program
Bureau of Special Medical Services
Health and Human Services Building
6 Hazen Drive
Concord, NH 03301-6527
(603) 271-4533

NEW JERSEY

Doris S. Kramer, M.S.
Coordinator, Genetic Services Program
Prevention Services
Special Child Health Services Program
New Jersey Department of Health
120 South Stockton Street
CN 364
Trenton, NJ 08625
(609) 984-0775

NEW MEXICO

Jeffrey M. Davis, M.D., M.P.H.
Chief, Maternal and Child Health Bureau
New Mexico Health and Environment Department
P.O. Box 968
Santa Fe, NM 87504-0968
(505) 827-0020

NEW YORK

Thomas W. Parham
Genetic Project Coordinator
Department of Health
1308 Empire State Plaza Tower Building
Albany, NY 12237
(518) 474-2050

NORTH CAROLINA

Elizabeth G. Moore, M.S.W.
Director Genetics Program
Division of Health Services
Department of Human Resources
P.O. Box 2091
Raleigh, NC 27602
(919) 733-7437

NORTH DAKOTA

John T. Martsolf, M.D.
Director, Medical Genetics Division
Department of Pediatrics
University of North Dakota Medical School
501 Columbia Road
Grand Forks, ND 58201
(701) 777-4277

OHIO

Virginia Miller, M.P.H., M.S., R.N.
Genetics Program Coordinator
Department of Health
P.O. Box 118
246 North High Street
Columbus, OH 43216
(614) 466-8804

OKLAHOMA

Vickie Stumbaugh, Ph.D.
Genetics and Metabolic Screening Coordinator
Oklahoma State Department of Health
1000 Northeast Tenth Street
P.O. Box 53551
Oklahoma City, OK 73152
(405) 271-4471

OREGON

Robert D. Koler, M.D.
Chairman, Department of Medical Genetics
Oregon Health Sciences University
3181 S.W. Sam Jackson Park Road
Portland, OR 97201
(503) 225-7703

PENNSYLVANIA

Daniel L. Brant, M.S.W.
Director, Genetic Diseases, Testing and Counseling Program
Division of Maternal and Child Health
Pennsylvania Department of Health
P.O. Box 90
Harrisburg, PA 17108
(717) 787-7440

PUERTO RICO

Pedro J. Santiago-Borrero, M.D.
Director, Genetic Diseases Screening Program
University Children's Hospital
University of Puerto Rico Medical School
G.P.O. Box 5067
San Juan, PR 00936
(809) 765-2363

RHODE ISLAND

William H. Hollinshead, M.D.
Chief & Medical Director
Division of Family Health
Department of Health
75 Davis Street, Room 302
Providence, RI 02908
(401) 277-2312

SOUTH CAROLINA

Robert H. Buchanan, Jr.
Deputy Director
South Carolina Department of Health
and Environmental Control
Division of Children's Health
Bureau of Maternal and Child Health
2600 Bull Street
Columbia, SC 29201
(803) 758-5491

SOUTH DAKOTA

Virginia P. Johnson, M.D.
Director, Birth Defects Genetics Center
University of South Dakota
School of Medicine
414 East Clark Street
Vermillion, SD 57069
(605) 677-5623

TENNESSEE

Joan Furman Seaborg, R.N., M.S.N.
Director of Center Based Programs
Perinatal/Genetics
Maternal and Child Health Section
Department of Health and Environment
100 Ninth Avenue North
Nashville, TN 37219
(615) 741-7335

TEXAS

Gilbert Levine, M.D., Director
Division of Maternal and Child Health
Texas Department of Health
1100 West 49th Street
Austin, TX 78756
(512) 458-7700

UTAH

John C. Carey, M.D., M.P.H.
Department of Pediatrics
Division of Medical Genetics
University of Utah Medical Center
50 North Medical Drive
Salt Lake City, UT 84132
(801) 581-6956

VERMONT

H. Eugene Hoyme, M.D.
Director, Vermont Regional Genetics
University of Vermont
College of Medicine
A115 Medical Alumni Building
Burlington, VT 05405
(802) 658-4310

VIRGINIA

Laura Funkhauser, M.D., M.P.H.
Genetics Program Director
Bureau of Maternal and Child Health,
Virginia Department of Health
109 Governor Street
Richmond, VA 23219
(804) 786-7367

WASHINGTON

Roberta Spiro, M.S.
Health Services Administrator
Genetics Services Section
Department of Social and Health Services
1704 N.E. 150th Street
Seattle, WA 98155
(206) 545-6783

WEST VIRGINIA

West Virginia University Medical School
Morgantown, WV 26506
(304) 293-4451

WISCONSIN

Raymond Kessel, Ph.D.
Statewide Genetics Services Network
104 Genetics Building
445 Henry Mall
University of Wisconsin
Madison, WI 53706
(608) 263-6355

WYOMING

R. L. Meuli, M.D.
Director, Family Health Program
Division of Health and Medical Services
Hathaway Building, Fourth Floor
Cheyenne, WY 82002
(307) 777-6297