

# The Parkinson's Disease Information and Research Center

#### SAMUEL J. WADDELL

THE SPECIALIZED information center is an example of a trend in science librarianship which will become, increasingly, a topic of discussion and interest to those persons who hope to facilitate and enlarge channels of communication between scientist and scientist and between scientist and layman.

To cope with the avalanche of biomedical literature, to serve the needs of neurologists engaged in clinical practice and research, and to implement the services of the National Library of Medicine (NLM), the National Institute of Neurological Diseases and Blindness, Public Health Service, decided early in 1963 to establish a national network of specialized neurological information centers supported by contract funds. The first center to be organized as part of this network was the Parkinson's Disease Information and Research Center at Columbia University Medical Library, housed within the Columbia-Presbyterian Medical Center.

As the Institute visualized these neurological information centers, they would be based in large university biomedical libraries attached to teaching hospitals where neurological research is in progress. The centers would collect, store, retrieve, and disseminate information about their particular subject areas. They would

Mr. Waddell is head of the information services section of the Parkinson's Disease Information and Research Center, Columbia University College of Physicians and Surgeons, New York City.

also provide comprehensive library service, search, screen, and analyze literature, standardize and define nomenclature, store and retrieve information by using automated methods, and prepare the results of research for publication. The service would be on a national and, when possible, an international scale. Critical reviews would be published and symposiums would be held. These objectives would be accomplished by the collaboration of scientists and librarians.

The Institute divided neurological research into the following five subject groups: (a) basic sciences covering neurological research, including anatomy, physiology, pharmacology, chemistry, and pathology, (b) clinical neurological difficulties, (c) vision and diseases of the eye, (d) speech, hearing, and disorders of communication, and (e) other neurological difficulties. The Parkinson information center relates to the first and second areas because research in the laboratory and treatment in the clinic deal with disorders of the motor area of the brain. The Brain Information Service at the University of California at Los Angeles covers brain physiology and thus may eventually relate to all the subject areas. The Vision Information Center at Harvard University covers the third area, and the Information Center on Hearing. Speech, and Disorders of Human Communication at Johns Hopkins University covers the fourth. The fifth area remains to be defined and developed in the future.

The packaged information products of the

centers are to be in exchangeable and compatible forms, eliminating unnecessary duplication of effort. Librarians are collecting, identifying, and processing data for input and storing it for retrieval. Scientists are defining terminology for librarians and evaluating literature, preparing reviews, giving lectures, and organizing meetings and symposiums. This combination of efforts reflects the viewpoint expressed by the President's Science Advisory Committee in its report, "Science, Government and Information," published in 1963 by the U.S. Government Printing Office.

This study, known as the Weinberg Report, recommended that the scientific community cut down on quantity and strengthen quality in publishing. The Committee also suggested that scientists assume more responsibility for the eventual retrieval of the papers they write; for example, in assigning titles to articles, they should choose keywords clearly indicative of the subject matter, and these keywords should be taken from special authority lists or thesauri.

#### The Parkinson Information Center

These recommendations have played a major role in the formation of procedures at the Parkinson information center. The scientific staff, by evaluating neurological literature and writing critical reviews, can help to raise standards of quality in publishing, and scientists and librarians, working together, have produced a thesaurus, or controlled vocabulary, as a guide to subject control and retrieval of the literature. This thesaurus, called Parkinson Thesaurus (PATH), has been expanding for 2 years and now contains about 5,000 entries. The skeleton of this thesaurus consists of several hundred terms from the National Library of Medicine's Medical Subject Headings (MeSH). Other terms have been taken directly from the literature of Parkinson's disease and related disorders. The terms allow indexing in maximum depth. The thesaurus is open ended; that is, new terms can be added and old terms deleted if necessary.

The National Library of Medicine, however, in attempting through MeSH to provide subject headings for all biomedical literature, has had to use broad concepts. As a result, readers interested in specific information such as epidem-

iology sometimes find that it has been lost in the indexing process, and the headings the epidemiologist would expect to find are missing or have been added to MeSH only recently. As a centralized national library, NLM cannot index literature to a depth that will satisfy all the users of the Index Medicus or MEDLARS (NLM's Medical Literature Analysis and Retrieval System). Therefore, each specialized information center is developing its own vocabulary, and all will be related to the library's Medical Subject Headings. To indicate to readers which subject headings are from MeSH and which are from the Parkinson Thesaurus, the Parkinson information center inserts its headings in parentheses.

#### Services of the Center

Among the most useful services the center provides are the bibliographic search, and the compilation of bibliographies on demand. This service is similar to the National Library of Medicine's MEDLARS. The specialized information center, however, by indexing the literature to a greater depth than MEDLARS, can retrieve subjects of more specificity and produce lists of citations to literature which will be more directly relevant to each reader's request. In compiling demand bibliographies, the specialized information center searches for pertinent literature not covered by MEDLARS in such sources as Chemical Abstracts and Bulletin of Hygiene, enlarging the scope of subject coverage to include more peripheral areas.

Another current service is the production of a biweekly alerting list. This publication, "Parkinson's Disease and Related Disorders: Citations from the Literature," is mailed to individual scientists, departments of neurology, and biomedical libraries throughout the world where there is active research on Parkinsonism. The publication lists citations to recent documents on Parkinsonism and Parkinson-related research (see figure).

Each citation contains more information than a standard bibliographic reference and, in addition to authors, title, pagination, and date, it gives the number of entries in the author's bibliography, the country of origin of the document, the language in which it is written, and a summary in English. The citation contains as

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1966 DOCUMENT CITATION
1967 DOCUMENT CITATIONS
                                                          The following citation represents a document published in
                                                      1966 which has been recently received or identified by the
       04060pc967
                                                      Center and is listed here for the first time.
Maekawa, K.
Purpura, D.P.
                                                             04143pc966
Properties of spontaneous and evoked synaptic
                                                      Dubois, J.
  activities of thalamic ventrobasal neurons.
                                                      Mazars, G.
                                                      Marcie, P.
Journal of Neurophysiology 30(2):360-381.
  March 1967.
                                                      Hecsen, H.
       39 Refs.
                   /Experimental/ Eng. U.S.A.
                                                      Étude des performances aux épreuves linguistiques
Thalamus - microelectrode recordings
                                                         des sujets atteints de syndromes parkinsoniens.
Neurons - microelectrode recordings
                                                         [Study of the performances in linguistic tests
(Evoked potentials)
                                                          of subjects affected by parkinsonian syn-
(Excitatory postsynaptic potentials)
 Lemniscus medialis) - electric stimulation
                                                      Encephale 55(6):496-513, Nov.-Dec. 1966.
(Gyrus sigmoideus) - microelectrode recordings
                                                             10 Refs. /Clin. Study/ Fr. France
                                                      (Parkinson's disease) - physiopathology
       04144pc967
                                                      Speech disorders
Pletscher, A.
                                                      (Parkinson's disease) - surgery
Bartholini, G.
Tissot, R.
Metabolic fate of L-[14 C] DOPA in cerebro-
  spinal fluid and blood plasma of humans.
Brain Research 4(1):106-109, Feb. 1967.
11 Refs. /Clin. Study/ Eng. Holland
DOPA - blocd
DOPA - cerebrospinal fluid
DOPA - metabolism
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Example of document citations available from the center's biweekly alerting list

many as six subject headings and the category or type into which the document falls; for example, experimental or clinical study. At a later stage of processing, an evaluation symbol is added to indicate how the document was rated for quality by the scientific staff, plus an indication of the availability of a full translation.

The information center also offers other services to its clientele. References accompanying manuscripts or galley proofs will be verified and corrected by librarians on the staff. Translations of documents published in foreign languages are advertised in "Parkinson's Disease and Related Disorders" and distributed free of charge; photoduplicating services are provided for intramural scientists only.

#### Structure of the Center

The information center is administered part time by the Columbia University medical librarian, and full time by the head of the information services section. The project director, a professor of neurology, is an adviser.

The staff is divided into the following four units:

The bibliographic unit searches and screens literature for input, assigns identification numbers and bibliographic descriptions, proofreads all print produced from punched cards, and maintains control files.

The thesaurus and indexing unit is responsible for subject control, literature analyses, thesaurus building, and literature searches for output.

The systems unit plans for automated data processing and the steps leading to it and operates the equipment. This unit coordinates activities with the thesaurus unit in planning search strategy for future information retrieval.

The clerical unit provides secretarial services, photocopying and multilithing, messenger service, and maintains an international directory file of scientists working on Parkinson-related research.

## Sources and Processing of Input Data

The scope of subject matter of the Parkinson information center is delineated at present by interest profiles on about 38 affiliated scientists. Interest profiles were developed through written questionnaires followed by interviews. Profiles

are updated periodically to insure that a record is made of each scientist's latest research activity. The librarians in the bibliographic unit who screen incoming literature must first become thoroughly familiar with interest profiles. Avenues of research tend to fall into patterns, and the interests of the Parkinson scientific group at Columbia are representative of the interests of scientists in other locations who are conducting research on the same disorders. The information center maintains a file of interest profiles on more than 2,500 scientists who have published articles on Parkinson-related subjects during the past 5 years.

Parkinson-related literature appears in books, journals, indexing and abstracting services, abstracts of papers presented at meetings, dissertations, technical reports, and films. Pertinent literature is identified in the following ways:

- 1. Daily incoming mail is scanned. Columbia Medical Library currently receives about 4,500 periodical titles annually.
- 2. About 300 indexing and abstracting services are scanned, including special bibliographic services such as *Industrial Hygiene Digest*, or those published by government-controlled information agencies, such as the *Bulletin Signalétique* of France. This is a method of picking up citations to articles in journals which the library does not receive.
- 3. References at the ends of articles are examined for possible inclusion and then checked against a master author file which contains citations to all the literature in the system. This file prevents accidental duplication.
- 4. New books are examined as soon as they have been cataloged.

When a Parkinson-related document is found, it is given an identification number and the book or periodical in which it appears is sent to a clerk who writes in longhand the necessary bibliographic description on a document processing worksheet. The document then goes to a literature analyst, or indexer, who assigns descriptors, or subject headings, to the document, selecting them from the Parkinson Thesaurus. More than 40 descriptors can be assigned to one document if the indexer believes that number is required to describe the document adequately. Descriptors are written on the reverse side of the document processing worksheet. The work-

sheet is designed so that a keypunch operator can copy from it without having to make decisions about capitalization or punctuation. The bibliographic description follows a rigid format.

If the document was published during the current year, it is listed in the weekly publication. To produce print from punched cards, the cards are fed through an electronic card reader coupled to an electric typewriter. A photo-direct camera processor makes a plate on which ink can be rolled for printing, and the list is printed on a 1250 Multilith offset-printing machine. Pages are collated and stapled together, stuffed into envelopes, and mailed. Address labels are also produced from punched cards.

### **Accomplishments Since 1964**

The information center is now in its fourth year of operation. It has sponsored three international symposiums which were attended by some of the leading scientists in neurological research. Two symposiums have been published; the third is being edited for publication in the spring of 1968. About 20,000 references to literature on Parkinsonism and related disorders have been stored on magnetic tapes. This data bank includes current and restrospective literature and is continually being enlarged. The mailing list for the biweekly alerting publication grows from week to week and now has more than 500 international subscribers.

Because of the shortage of trained persons, the information center has had to train indexers, keypunch operators, multilith operators, and computer operators. Job descriptions had to be written for positions which had not existed before in the Columbia University libraries system.

The center's services are not exclusively for neurologists. Any person working in the biomedical sciences or the paramedical professions can contact the Parkinson information center. We have supplied bibliographic information to pharmaceutical companies, law firms, newspapers, teachers, and students. In this sense, the center is serving the general public; however, a privately supported Parkinson Foundation within Columbia-Presbyterian Medical Center provides information for Parkinson patients and their families on home care. Each of the

three Parkinson symposiums has received prominent coverage in newspapers.

Parkinsonism by itself does not constitute a public health problem, but some neurologists believe that its incidence is increasing as the average person's lifespan increases. Because it is an incapacitating disease, it will have implications for Medicare and Medicaid. Statistics on the morbidity of Parkinsonism vary widely from place to place, so estimates of prevalence are far from exact. But movement disorders, if they are all grouped together, do affect large numbers of people. Since the neurological subject matter of the four information centers in the National Institute of Neurological Diseases and Blindness' network overlap one another, the centers will continue to cooperate and coordinate activities to provide information to the health professions. In the future, information centers on cancer, heart disease, and stroke may also be developed.

# Summary

In 1964 the Parkinson's Disease Information and Research Center at Columbia University was established by the National Institute of Neurological Diseases and Blindness, Public Health Service. It is the first neurological information center in a planned national network of specialized neurological information centers to be supported by contract funds.

This center is concerned with basic sciences covering neurological research, including anatomy, pathology, physiology, pharmacology, chemistry, and clinical extrapyramidal disorders.

Any person working in the biomedical sciences or the paramedical professions can use the services of the center. These services include (a) searches and bibliographies on demand, (b) publication of a weekly alerting list, which gives citations of recent documents on Parkinsonism and Parkinson-related research, (c) verification of references accompanying manuscripts or galley proofs, (d) development of interest profiles on scientists affiliated with the center or writing on Parkinsonism, (e) production of a thesaurus on Parkinson's disease, which now contains 5,000 entries, (f) translation of documents, (g) reproduction of documents on request, and (h) maintenance of a directory file of scientists working on Parkinson-related research. The information center is composed of the bibliographic unit, the thesaurus and indexing unit, the systems unit, and the clerical unit.

# National Study of Illnesses Caused By Clostridium perfringens

A national study to determine the frequency of food poisoning caused by *Clostridium perfringens* is being conducted by the Public Health Service in cooperation with State and local health departments.

The illness was first studied in Great Britain as early as 1945. It was not until 1960 that researchers, in what is now the National Center for Urban and Industrial Health in Cincinnati, Ohio, began developing a simplified method to isolate and identify the bacteria in foodborne disease outbreaks in this country.

A brochure describing the study and requesting participation was mailed to all the States and to a number of local health departments. Washington, Arkansas, California, Kentucky, New Jersey, Georgia, Maine, Wisconsin, and Michigan have already submitted bacterial cultures. Hopefully, there will be cooperation from the remaining States.

The project is divided into two parts. The National Communicable Disease Center is responsible for the serologic identification of the bacterial strains, and the National Center for Urban and Industrial Health will do the serologic characterization of these same strains.

Ideally, this research will establish the ability of scientists to identify food poisoning through analysis of the bacterial strains rather than examination of the contaminated food.

The study is expected to last from 3 to 5 years, depending on the extent of cooperation received from State and local health departments.