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#### VETERANS ADMINISTRATION

#### AGENT ORANGE REGISTRY -- AN OVERVIEW

# History:

The Agent Orange Registry was initiated by the Veterans Administration in mid-1978 in response to concerns expressed by Vietnam veterans who were increasingly worried that they may have been exposed to chemical herbicides which might be causing a variety of ill effects. VA Circular 10-78-219, dated September 14, 1978, established the framework of the Registry.

The circular also created a card file to record each examined veteran's name and address. This component of the Registry has changed as experience has dictated. Initially, a special summary was created to contain selected information and was retained in the medical record. In 1979, the procedure was changed so that the summary was submitted to the VA Central Office for encoding. The coded data was then entered into a computerized data base.

A special Data Analysis Task Force was formed in June 1980 when it became obvious that the Registry's data input procedures needed improvement. The Task Force recommended a number of changes during 1981 and, in August 1982, Circular 10-82-154 ordered an updating of the names and addresses for the veterans listed in the Registry. This was followed by Circular 10-83-38 that completely revised the reporting process in order to improve the coding of demographic and medical information, thereby permitting easier data retrieval.

Registry records consist of two components: the medical record maintained at the VA Medical Center where the veteran was examined and a computerized extract from that record. The veteran's medical record includes the full medical history, physical examination, laboratory reports and other clinical findings. The computerized extract, better called the "register," includes the veteran's name, address, the examining medical center, some information about the veteran's military service, an estimate of herbicide exposure and elements of the findings at the time of the physical examination. The computerized register constitutes an index to this nationwide set of medical records. A copy of the currently used code sheet is attached.

# Purpose

The principal purpose for which the Agent Orange Registry program was designed remains unchanged to the present time. It is a process which serves all veterans who are worried about the possible adverse health effects of their exposure to herbicides while serving in Vietnam. It provides the veteran an opportunity to receive a complete health evaluation and answers to questions concerning the current state of knowledge regarding the relationship between herbicide exposure and subsequent health problems.

Following completion of the examination the veteran is given the results of the physical exam and laboratory studies. This information is provided to the veteran by both a face-to-face discussion with a physician familiar with the health aspects of the Agent Orange issue as well as a follow-up letter summarizing the results of the examination.

The Registry serves an important second purpose in that it enables the VA to provide veterans current information as it develops regarding their concerns. In addition it would permit the VA to contact veterans for further testing in the event that continuing research efforts should make this action advisable. The Registry serves yet another purpose, namely, to provide a means of detecting clues or suggestions that specific health problems or unexpected health trends are showing up in this group of veterans. Such clues would then form the basis for the design and conduct of specific epidemiological studies.

## Limitations

Because of the self-selected nature of the Registry participants, this group of veterans cannot, with any scientific validity be viewed as being representational of Vietnam veterans as a whole. Therefore the health-related information contained in the data base cannot be used directly as an epidemiological tool. The information can, however, be used to detect suggested health trends, as noted above, and can provide some descriptors as to the characteristics of the group itself. For example, it is possible to show the numbers in each branch of military service, the period(s) of service in Vietnam, the kinds of symptoms the veterans are experiencing and some of the results of the physical examinations. However, since participation in the Registry program is entirely voluntary, one cannot make statistically valid comparisons with other groups of veterans or non-veterans.

#### Summary

The Agent Orange Registry remains the most effective means of identifying concerned Vietnam veterans. Any eligible Vietnam veteran expressing a concern relating to exposure to

herbicides is encouraged to participate in the Registry, which includes a thorough medical examination. During the examination, the veteran is asked demographic and identifying information, military information including branch of service and dates of service in Vietnam, and how he perceives his exposure to Agent Orange. A complete past medical history is obtained and documented. The veteran is then provided a physical examination which includes several base-line laboratory studies. Additional tests/consultations may be ordered depending on the veteran's physical condition or past medical history.

As of December 31, 1983, the VA had completed 130,220 initial Agent Orange Registry examinations of which approximately 13,600 have utilized the new code sheet. In addition, 31,471 follow-up examinations have been performed.

*				P,	ART II — To be completed by	Exami	ning P	hysician					-				
22. VE				ETERANS COMPLAINT(S) (MAS coders, enter ICD9-CM code at right)										204	205	206	207
21, DATE OF EXAM												7	8				
			. a.	a,									208	209	210	211	212
MONTH DAY YEAR		Ь.	b.								7	8					
(197-198) (199-200) (201-202)												213	214	215	216	217	
			c,										7	8			
23, Does veteran attribute chief complaint				218									L	- <del></del>		L	221
to Agent Orange exposure?					defects among veteran's children?		1 No workup. No consultation								Dermatology		
, , , , , , , , , , , , , , , , , , , ,					1 No 2 Yes, conceived after Vietnam Service	<u> </u>	done.  2 Workup/consultation done. Diag-							b, Neurology			222
24. Number o	f veteran's cor	mplaints?		219	3 Yes, conceived before		nosis doubtful.  3 Workup/consultation done. Diagnosis established.							c. Psychiatry			223
(Code 5 c	or more as "5"	7			Vietnam Service 4 Yes, both before and												
					after Vietnam Service 4 Workup/consultation done. No diagnosis.								d. Infertility/ Genetic Problem			224	
28. LIST UP	TO THREE DI	EFINITE DIA	GNOSES (	MAS c	oders enter ICD9-CM Codes at right	2	AB AL			<b>.</b> _			······································				
									(225)	(226)	(227)	(228)	(229)				
a,								(230)	(231)	(232)	(233)	(234)					
<u>6.</u>								(235)	(236)	(237)	(238)	(239)					
c.  29. EVIDENCE OF NEOPLASIA (Specify diagnosis) ENTER "1" FOR YES AND "2" FOR NO IN BLOCK 240.  (246)							(240)	(241)	(242)	(243)	(244)	(245)					
30. If no disease is found, enter "1" in block at right, otherwise, leave blank.			<del></del>	<u></u>	<u> </u>						T	ļ	0.40	250		251	252
			246	31. Enter year of onset for each diagnosis listed above. If unknown, leave blank.						240	2ND DX	249	200	3RD DX	201	202	
32. DISPOSITION (Enter one code in each block)					1 = Yes 2 = No (Code tiem d separately according to instructions)												
a. Exam completed				253	b. Hospitalized at the VAMC for further tests	254		lospital or treat	ized at ( niest	he VA	AMC				256		
			256	If veteran was referred for VA			CL	NIC CL		NIC	CLI	NIC	CLI	NIC	CLI	NIC	
d, Referred care	for VA outpat	lient			outpatient care, indicate two di code for the clinic at right. (See clinic codes listed on VAF 10-2	r*		(257)	(258)	(259)	(260)	(261)	(262)	(363)	(264)	(265)	(266)
e. Referred to private physician,			267	f, Biopsy			268	g. S	pecime	ns to be	sent					269	
non-VA clinic or non-VA hospital,					to AFIP												
33. REMARK	KS To the second																
34. NAME OF EXAMINER (Please print)						35. TITLE OF EXAMINER											
36. SIGNATU	JRE OF EXAM	MINER	<del></del>				<u></u>		<del></del>				· · · · · · · · · · · · · · · · · · ·		<b>. </b> .		·