

C.P. Section 6.3.1 Handling of ALD Backlog Cases

	Adrenoleukodystrophy (ALD) Protocol – NBS <i>Metabolic</i>	<i>September 21, 2016 Implementation Date</i>
	Backlog Cases	
<i>GDL ALD Lab</i>	MS/MS for C26:0 Tier 1	<ul style="list-style-type: none"> Initial VLCFA Tier 1 - Inconclusive
<i>GDL ALD Lab</i>	HPLC MS/MS for C26:0 Tier 2	<ul style="list-style-type: none"> VLCFA Tier 2 - Positive GDL ALD Lab sends email to ALD Backlog Coordinator notifying them of Tier 2 Positive sent to Greenwood Genetic Lab for further testing Ship specimen to Greenwood Genetics Lab with tracking
<i>Greenwood Genetics Lab</i>	ABCD1 Gene Sequencing Tier 3	<ul style="list-style-type: none"> Greenwood Genetics Lab ABCD1 Gene Sequencing VLCFA Tier 1 and 2 held pending sequencing Send sequencing result to GDL ALD Lab
<i>GDL ALD Lab</i>	Create ALD Backlog Mailer	<ul style="list-style-type: none"> Create mailer for ALD Positive that includes Tier 1, Tier 2, and ABCD1 Sequencing results when Tier 3 Sequencing complete
<i>GDSP</i>	Upload ALD Backlog Mailer in SIS	<ul style="list-style-type: none"> Upload ALD Backlog Mailer in Case Attachments in SIS
<i>GDSP</i>	Notify ASC of ALD Backlog Positive	<ul style="list-style-type: none"> Call and email ASC of ALD Backlog Positive
<i>GDSP</i>	Create Non-Screened Client in SIS	<ul style="list-style-type: none"> Create non-screened client in SIS Add dummy case resolution
<i>GDSP</i>	Merges Clients in SIS	<ul style="list-style-type: none"> Merge clients in SIS to allow SCC to enter Service Report Enter case notes
<i>GDSP</i>	Add ALD Backlog Positive Case to Headline Case Screen	<ul style="list-style-type: none"> Enter tracking event TE142 in SIS to add ALD Backlog Positive case to the ASC Headline Case Screen
<i>ASC</i>	ALD ABCD1 Mutation Positive	<ul style="list-style-type: none"> SIS Headline Case Screen notification to ASC

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		<ul style="list-style-type: none"> • If case was previously positive, the case status will appear as “Open” • If case was previously negative, the case status will appear as “New” • If case was previously positive, the interpretation will remain the same • Contact NICU or PCP within 2 Business Days • Notify of result and need for referral to Metabolic Center. • Fax/Email all result mailers, ALD Fact Sheet and Request Family Notification • Refer to Metabolic Center with TE 161 • Track 14 days to confirm family connected to Metabolic Center • If the center has difficulty making contact with family, offers assistance in making a referral to public health nursing • Documents all attempts at notification, interactions with physicians and parents using tracking events and case notes in SIS. • Reports unusual occurrences such as missed cases, anomalous/inconsistent results, lost to follow-up cases, delays in contacting family, etc., to the NBS Nurse Consultant/ASC Contract Liaison.
<i>Metabolic Center</i>	ABCD1 - Mutation Positive	<ul style="list-style-type: none"> • Contact family for Initial Visit and Counseling • Initiate additional Confirmatory and baseline testing • Enter initial ALD Service Report in SIS • Recall family per established protocol • Updates Case Resolution Report in SIS
<i>ASC</i>	Case Resolution and Closure	<ul style="list-style-type: none"> • Close case per Case Resolution diagnosis
<i>GDSP</i>	Adds Case to Registry	<ul style="list-style-type: none"> • Enters Backlog case in Registry