

Newborn Screening Hot Topic Webinar: NCAA Sickle Cell Requirement

Chat Box

00:20:39 Amy Gaviglio: Welcome everyone!! Please note that we will have poll questions and discussion after Kim's talk, but please put any comments or questions in the chat as you think of them!

00:24:02 Sarah Bradley: There was as change in 2022, right? Our understanding is that in the past the NCAA allowed students to sign a waiver rather than be tested or provide a test report but that is no longer allowed.

00:24:30 Brielle Easton: I read that as of Aug 1, 2022 athletes are not allowed to waive the requirement. New bylaw from NCAA

- 00:24:34 Krystal Baumert: That is correct there use to be a waiver that students could sign.
- 00:24:48 Allison Forkner: Yes, now they can not sign the waiver.
- 00:24:51 Sarah Bradley: Our volume has dramatically increased this summer vs. past years
- 00:24:55 Fran Altmaier: That is likely the reason for the significant uptick this year in requests
- 00:25:00 Allison Forkner: Ours as well!!
- 00:25:37 Allison Forkner: Fall late summer
- 00:25:45 debra freedenberg: summer/fall
- 00:25:56 debra freedenberg: 10-20
- 00:25:59 diane driver: My daughter is an athlete and was told they can no longer sign a waiver.
- 00:26:04 Amanda Ingram: Late summer
- 00:26:05 Krystal Baumert: I see poll questions, but it does not allow for it to be submitted.
- 00:26:17 Jordan Shover: Over 100 per week in Summer
- 00:26:20 Colleen Clarke: summer/fall
- 00:26:20 Jodi Philippon: LATE summer about 6 per week

00:26:21 Brielle Easton: <u>https://ncaaorg.s3.amazonaws.com/governance/d1/legislation/2021-</u> 22/2022D2Gov_LegPropQA.pdf

- 00:26:23 Sharon Linard: Mid and late summer
- 00:26:28 Karyn Dynak: summer
- 00:26:42 Mary Kleyn: Late summer, about 20-30 per week

00:26:55 Sharon Linard: we receive more than 10 a week

00:27:01 Kimberly Noble Piper: Same in Iowa, @Sarah Bradley much more this year

00:27:09 Joyal Meyer: ND only started screening for hemoglobin disorders in 2003, so we just this year started receiving these requests.

00:27:11 Michelle Bargren: mid to late summer is busiest...with 10-20 per week, if not more some weeks. Iowa does have a process

00:27:22 Sarah Bradley: We have received 131 requests just since this past Monday

00:27:29 Jodi Philippon: yes

00:27:29 debra freedenberg: yes

00:27:36 Bender Bender: Can you leave the pool results up longer

00:27:47 stanley Sciortino: 1000s

00:27:48 Jodi Philippon: sure

00:27:49 Lorrie Folmar: Alaska, like North Dakota, only started screening in 2003. This is the first year we have been able to fulfill requests

00:27:55 Joyal Meyer: 😳 Sarah!!

00:28:31 Jennifer Baysinger: In OK we require a release of info and will only submit the results back to the physician, so that if needed there is a medical professional that can interpret results.

00:28:36 Sarah Bradley: We have a specific request form that parents or student athletes (if > 18) fill out, or PCPs can use our regular record request form

00:28:38 Fran Altmaier: we request forms on our website www.aznewborn.com under the contact us tab

00:28:46 Sara Etienne: Oregon's retention plan now only has NBS records for 6 years so we have zero records but we receive tons of calls and requests

00:28:49 Brielle Easton: NJ - high peak we got 100+ a week. Currently we have a release form, over 18 they need to fill out and sign. Fax back or email back. Processed in order received, currently 7-10 day turnaround. Can go to PCP or directly to the school.

00:28:54 Allison Forkner: Indiana has two methods of requesting NCAA sickle results. Happy to elaborate!

00:29:03 stanley Sciortino: We release by consent in CA.

00:29:31 Sarah Bradley: our turnaround has been usually 1-2 business days - if we don't keep up with the volume they call, email, etc. and that is overwhelming

00:29:37 Krystal Baumert: In Nebraska we can only release the results to physicians. We do not release them to colleges because it is not appropriate to release a newborn screening report that

contains genetic information to the college. They are not entitled to all the genetic information on the screening report.

00:30:19 Sydney Williamson-White: We will only release records to the individual's provider only. Our contracted lab provides us with a report that has sickle cell results only.

00:31:01 Mary Kleyn: We release based on physician request. If the person doesn't have a provider, there is an option to request through our Legal area, but that can take up to 30 days.

00:31:03 Jodi Philippon: In Maine, we have a consented process. The student accesses the form either via our state website or PCP office. Once received, we request the legacy lab report, then forward to the PCP office identified.

00:31:15 Sarah Bradley: we do not email reports - they must be sent out via fax or mail

00:31:16 Michelle Mills: Kansas Customer Service will release to providers and parents, if parents submit a notarized request. They do recommend parents have the provider request results.

00:31:28 Mandie Loehe: Wisconsin releases reports to providers only with a completed request form. If individuals are requesting results they need to go through a more legal process through our administration department.

00:31:29 Jodi Philippon: If the student is under 18, then the parent/guardian completes and signs

00:31:39 Brielle Easton: if we don't do a solubility test does that mean the report doesn't meet the NCAA requirements?

00:31:49 Amy Gaviglio: @Brielle - that will be our next big discussion! :)

00:32:07 Krystal Baumert: In Nebraska it is in our state regulations that the hospital medical records have to keep the newborn screening results in the individual's medical record for 25 years.

00:32:57 Kimberly Noble Piper: For those that email the results - do you email them using a secure method, e.g., encrypted mail?

00:33:10	Brielle Easton: NJ - any email we send securely
00:33:11	Fran Altmaier: Arizona sends via secure email
00:33:41	Michelle Mills: Kansas sends any info via encrypted email.
00:33:57 PCP offices.	Jodi Philippon: We use Ringcentral electronic faxing that is secure to forward results to
00:33:59	Ellen Willmore: Texas only faxes or mails. No email
00:35:59 https://www.c	stanley Sciortino: See: dph.ca.gov/Programs/CFH/DGDS/Pages/nbs/athletestraitresults.aspx
00:36:03	Sharon Linard: Ohio asks for current ID or Notary signature and stamp

00:36:17 Ellen Willmore: TX release

https://www.dshs.texas.gov/lab/PDF/formReleasePHIenglish.doc

00:36:44 Sydney Williamson-White: How do folks who verify pt. identity manage the fact that NBS are often listed under the birth parent's last name vs. legal name?

00:36:49	Allison Forkner: No cost in Indiana
00:36:51	Joan Ehrhardt: Illinois charges parents/individuals for requests.
00:36:54	Allison Forkner: Indiana does not charge.
00:36:54	Joyal Meyer: No for ND
00:36:58	Jodi Philippon: Maine is not currently charging for these requests.
00:37:01	Jennifer Baysinger: OK does not charge
00:37:02	Jordan Shover: No for PA
00:37:05	Mandie Loehe: No charge in WI
00:37:05	Amanda Ingram: No for TN
00:37:09	Sarah Bradley: No charge in NY
00:37:11	Fran Altmaier: no charge in AZ
00:37:12	Roger Eaton: MA does not currently charge
00:37:14	Joan Ehrhardt: Illinois does not charge providers. So we let families know that.
00:37:19	Sharon Linard: Ohio - no charge
00:37:20	Mary Kleyn: No charge in MI
00:37:31	Brielle Easton: NJ - no.
00:37:32	stanley Sciortino: CA does not charge
00:37:43 any longer. Kar	Michelle Mills: In Kansas, some hospitals are telling patients they don't have the infonsas does not charge.
00.37.55	Pamela Clark: Georgia does not charge

00:37:55 Pamela Clark: Georgia does not charge.

00:38:24 Carol Johnson: No for IA

00:39:19 Michelle Mills: <u>https://sicklecelltesting.pwnhealth.com/</u>

00:39:25 TaLana Hughes: Does anyone partner with Sickle Cell Disease Associations to assist with sharing NBS SC test results, education? We the Sickle Cell Disease Association of Illinois we partner with IDPH so If and when families connect with us we are able to get a copy of NBS test results to assist with education/records/connection with providers etc...

00:39:30 Jelili Ojodu: @Sarah, 131 requests since Monday... approximately what is the% effort dedicated to this effort in NY?

00:40:03 TaLana Hughes: We also get direct requests for testing/results from patients/families

00:40:29 Joan Ehrhardt: HI TALANA!! Thank you!!

00:40:40 Ashley Comer: <u>https://www.hhs.gov/hipaa/for-professionals/special-topics/clia/index.html</u>

00:40:44 Sharon Linard: Why do states retain screening results for more than 18 years?

00:40:50 Sarah Bradley: @Jelili - one person used to be assigned to this staff but we've had to assign two additional staff this summer and that has still some days not been enough since that is not their only responsibility, so then it's "all hands on deck"

00:41:06 Mandie Loehe: WI retains nbs reports for 28 years

00:41:58 Krystal Baumert: In Nebraska we retain newborn screening results for 29 years.

00:42:19 stanley Sciortino: CA: It would cost us too much to charge for the results.

00:42:40 Mark Goodwin: yes, Talana. NBS results have life course implications.

00:43:14 Krystal Baumert: This puts state programs in a very different spot because we can not be 100% sure it is that individual's blood on that filter paper.

00:43:16 TaLana Hughes: Heyyy Keisha and Mark!!

00:43:29 TaLana Hughes: Hi Joan thank you!

00:44:01 Jodi Philippon: Hello Amy, Laurie, and Carol!

00:44:20 Annie Ross - Womack: Greetings Tanana

00:44:22 Joyal Meyer: Can we discuss Kim's initial comment about the NCAA requesting the sickle cell solubility test and if there are any states that actually do that? For those of us who do not, then do we need to work together to provide an unified statement from NBS programs explaining we do not have the results they are requesting.

00:44:35 Amy Gaviglio: Yes @Joyal - that is our next topic!

00:44:39 Jelili Ojodu: States retain residual DBS for different reasons and varying amount of time @Sharon. Mostly for internal QI, method development and improvement.

00:44:47 Jelili Ojodu: see <u>https://www.newsteps.org/data-resources/reports/dbs-retention-</u> <u>report</u> for more info

00:44:49 TaLana Hughes: And alot of our families are relieved after speaking with us and finding out that they don't have to be stuck (re-tested) and can actually utilize their NBS test results!

00:45:46 TaLana Hughes: Hey Annie 🙂

00:45:54 Annie Ross - Womack: If you are sending newborn screening results to coaches, trainers, parents and students, how can they understand the results?

00:45:58 Carol Johnson: TaLana, Keisha et al - what a great thing you do talking to these families! THANK YOU!

00:46:27 Joyal Meyer: @Sharon - we save NBS results indefinitely and NBS dried blood spot cards for 18 years

00:46:28 Sharon Linard: The coaches have no idea what to do with abnormal results - they have guidance for FAS, but not for other traits FAE, FAD etc.

00:46:43 Jenn Weaver - IN Dept of Health: Thank you for explaining your process, Kisha! I completely agree. Having a standardized method of requesting and delivering this information would expedite this process to ensure students' activities are not interrupted.

00:47:05 Amy Gaviglio: Agreed that we need to think about this more than just release of results, but that providing support and education needs to be part of this process. This is more than just checking off a box

00:47:42 Kisha Hampton- IHTC: correct!!!

00:47:59 julie Raburn-Miller: In MO parents who have requested the NBS results are doing so because they don't want to pay for an office visit and the test. These parents view it as cost savings.

00:48:02 Ashley Comer: It does look like it can charged "Under the HIPAA Privacy Rule, patients, patient's designees and patient's personal representatives can see or be given a copy of the patient's protected health information, including an electronic copy, with limited exceptions. In doing so, the patient or the personal representative may have to put their request in writing and pay for the cost of copying, mailing, or electronic media on which the information is provided, such as a CD or flash drive. In most cases, copies must be given to the patient within 30 days of his or her request." https://www.hhs.gov/hipaa/for-professionals/special-topics/clia/index.html

00:48:05 Pamela Clark: Should we not discuss timing of obtaining results. Why are high school students playing sports not given this information? Wouldn't they be impacted health wise when playing.

00:48:33 Amy Gaviglio: GREAT question @Pamela

00:48:43 Krystal Baumert: Agreed, Pamela.

00:49:17 Sharon Linard: Ohio is getting some requests for younger athletes on select teams

00:49:43 Kisha Hampton- IHTC: great questions Pamela. They should be looking at this at the high school level. There have been a few athlete deaths here in Indiana and in the back of my mind I ask myself- did they have a SCT???

00:51:28 Amy Gaviglio: How many states follow their trait results and ensure a Hgb electrophoresis/education is happening? Does this happen anywhere?

00:51:36 Fran Altmaier: Trait awareness is an important piece of the life course care

00:51:40 TaLana Hughes: Ditto to Keisha yes the earlier the better...we have kids even prior to high school that are playing organized sports as well

00:51:50 Kisha Hampton- IHTC: The primary care/pediatricians doctors should have some responsibility. It needs to be talked about so may years at each clinic visit.

00:51:52 Joyal Meyer: ND is just starting to have genetic counselors follow up with families who have children with hgb traits

00:52:10 Rae Blaylark: This is great dialogue! As a caregiver, community leader, CHW and previous member of the peds clinical team, I was the person who received the results and even for me, I had to work with the SCD MD and LEARN how to interpret the results AND how to best share results with families in an empowered way. I totally agree with Annie.

00:52:10 Jillian Chance: We have so much work to do prior to college (and so many kids don't play sports)

00:52:37 TaLana Hughes: Yes re-education by the pcp's and CBO's is great to keep reminding and repeating to families so they dont forget!

00:53:06 Mandie Loehe: In WI there is a program separate from our laboratory and stfu that follows up with providers for identified traits

00:53:12 Lorrie Folmar: Alaska does not follow traits after the initial report

00:53:16 Fran Altmaier: It also highlights the need for education to parents and providers to be aware of ALL NBS results because of the lifelong implications for many conditions

00:53:37 Pamela Clark: In Georgia, the DPH contracts with Sickle Cell Foundation to follow all trait results. They contact families and provide additional testing and education.

00:54:16 Jodi Philippon: in Maine we do not follow up after the initial lab report

00:54:39 Rae Blaylark: Disseminating results should also include referral information, whether to the CBO or to the local heme clinic (esp for disease findings).

00:54:52 Amy Gaviglio: YES @Rae (And Hi by the way!!)

00:55:10 julie Raburn-Miller: In MO we send a letter to the parent if their child has a trait along with information about that particular trait. We also state that if ithey have questions about the trait to contact us or a sickle cell center. In the insert we include in the letter we list the hemoglobinopathy centers they can contact for additional information.

00:55:27 Amanda Ingram: We do follow-up on traits if they get confirmation testing but if they are never confirmed we do not continue to follow after a few letters and a call to the provider recommending the confirmation testing. We are looking into possibly adding HGB results to out immunization record system so that when students have to get immunizations in middle school then those results are there and they could have a reminder that they have trait and also the students would have results when presenting immunization record to colleges and universities.

00:55:37 Kisha Hampton- IHTC: That is not good that the PCP's say this. The main reason they need to know is for future reproductive decisions. These reminders should go out at many different intervals as a child grows.

00:55:51 Amy Gaviglio: Thank you all for the great comments in the chat; I assure you that we will go through and collate and put something together that documents all of this GREAT content. With action plans moving forward. So keep the discussion coming!

00:56:15 Sharon Linard: I agree that education of pts/families is needed for hemoglobinopathies. The majority of Student athletes do not have SCT, so they would not be getting this education and would not know their trait status.

00:56:44 Kisha Hampton- IHTC: correct

00:57:11 Kisha Hampton- IHTC: yes it will help greatly.

00:57:20 Marilee Lowrey: Yes! This is something we're talking about doing in KS too - including HGB trait results I'm the immunization record portal.

00:58:55 Carol Johnson: What a fantastic webinar! So many wonderful ideas/suggestions and issues that need to be addressed. Very complex situation

00:59:25 Brielle Easton: does NBS meet the NCAA requirements if we don't do the solubility test

00:59:44 Sharon Linard: There should be a national response

01:00:06 Joyal Meyer: Yes @Brielle? If we aren't doing the correct test, then how do we respond?

01:00:17 Amy Burke: I agree. If the solubility test is what is required, I think that as a national program, a statement should be issued stating as such.

01:01:09 Joyal Meyer: It would be extremely unfortunate if something significant happened to someone and their trait was "missed" by screening?

01:01:45 Sharon Linard: My guess is that the NCAA would just change wording to allow IEF and HPLC tests.

01:01:57 Michelle Mills: A solubility test is considered screening. Yes, it is a positive or negative test. It is used in Blood Bank.

01:02:53 Amy Burke: Then perhaps NCAA would need to be educated on what constitutes a test vs screen

01:02:53 Bender Bender: I thought the legal settlement allowed for "prior testing" and NBS fit the bill

01:02:59 Carol Johnson: When Dr. Beth Tarini was at Iowa, we had just started to delve into how best to talk to families/adolescents about this issue. In the adolescent clinic at U Iowa, the pediatrician would talk to the teenager about their sickle cell status. Most teenagers would respond that they had NO idea that they had sickle cell trait. Many teenagers were upset that they didn't know. While overall

the teenagers and families were happy that this was discussed, some families complained because this caused the teenagers to be upset with their parents because they didn't tell them.

01:03:01 Ashley Comer: Not disagreeing that ideally follow up and education after NBS results needs to happen and that is an initiative the community should continue to pursue. However, because NBS is a screening and should not be used diagnostic or on its own is there a way to encourage NCAA to provide appropriate testing as part of physical etc.

01:03:02 Kimberly Noble Piper: Seems like there are at least two issues that need to be addressed with the NCAA - 1. The inappropriate use of newborn screening results as documentation of a "prior test" for Sickle Cell status, and 2. The NCAA's responsibility to all athletes, but especially those with SCT to assure a safe environment

01:03:09 Mandie Loehe: In WI we use IEF and reflex to HPLC. Our purpose is to identify DISEASE hemoglobinopathies and identifying traits is additional information.

01:03:12 Michelle Mills: IEF or HPLC would be more definitive than a solubility screening.

01:03:15 Krystal Baumert: In Nebraska newborn screening is a mandatory law so parent(s) can not refuse the screen. Various courts in Nebraska have enforced the law and state program staff have been sued personally for reporting screening refusals to county attorneys. Therefore, Dept. Legal Staff, Nebraska Advisory Committee, and state program staff take it very seriously about protecting genetic information. We release information to physicians as they are responsible under Nebraska state law to make sure the newborn screen is ordered, collected, and followed-up on. We do send a letter to the baby's mother when we have an abnormal newborn screening result for a hemoglobinopathy.

01:04:24 Fran Altmaier: Has anyone reached out to the NCAA? Could it be read that a solubility test can be done if no other results are available?

01:04:40 Kimberly Noble Piper: Exactly, Aaron. That's what needs to be presented to NCAA.

01:05:06 Cheryl Hermerath: Assume the athletes are required to have a physical before playing. Why isn't sickle cell a routine request as part of this physical. With the influx of money into NCAA programs and the new ruling that these athletes can also be paid, why is NBS footing the expense for providing results whe

01:05:34 Annie Ross - Womack: The colleges offer testing in some states.

01:05:36 Amy Gaviglio: interesting proposal @Cheryl - Kisha, Talana, etc. - thoughts on this approach?

01:05:36 Michelle Mills: <u>https://sicklecelltesting.pwnhealth.com/</u>. This is a solubility screening provided by Quest for approximately \$32.50.

01:05:41 Kisha Hampton- IHTC: I actually have called and left a message at the NCAA about two weeks ago about this and I have not received a reply as of yet.

01:06:47 Sarah Bradley: Good point Joyal

01:06:58 Allison Forkner - IN: Does anyone know where we can find a copy of this requirement from NCAA? Where is it documented?

01:07:18 George Dizikes: With regard to dealing with the NCAA, keep in mind that the large conferences (e.g., Big 10, SEC, etc.) should probably be included in these discussions, especially since they may replace the NCAA in coming years.

01:07:28 Brielle Easton: <u>https://ncaaorg.s3.amazonaws.com/governance/d1/legislation/2021-</u> 22/2022D2Gov_LegPropQA.pdf

01:07:35 Brielle Easton: new bylaw that they can't waive ^^

01:07:36 Amy Gaviglio: <u>https://www.ncaa.org/sports/2013/11/25/sickle-cell-trait.aspx</u>

01:07:43 Allison Forkner - IN: Thank you @Amy!

01:07:55 Ashley Comer: It feels like the rule was a checkbox activity and not a true solution to the problem they were trying to address. The fact that the medical community as Debbie mentioned was not in agreement sends red flags. Can we partner with pediatric hematologists etc to educate the NCAA?

01:08:07 suzanne canuso: If we really want to hit the target of providing timely and appropriate education to people, could we ask the NCAA to push to have sickle cell status testing as part of college physicals, leave newborn screening out of the equation?

01:08:51 Fran Altmaier: @roger, that is how I interpret it as well

01:09:10 Jodi Philippon: Suzanne, AGREED!

01:09:12 Rae Blaylark: We also should be considering the importance of including SC Trait results in the athlete's formal medical records. How might this be addressed within the SCDAA requirements?

01:09:13 Joyal Meyer: Something to consider... Which states would have time to draft individual letters to provide to athletes instead of providing them a report?

01:09:45 Brielle Easton: @joyal we barely have time to provide report in NJ due to population

01:09:46 Amanda Ingram: It seems like the NCAA is doing this to protect themselves from lawsuits and put the responsibility on the colleges and universities so they don't care about the issues that NBS programs are dealing with for these requirements to be met

01:09:48 Michelle Mills: Solubility is qualitative. https://www.fishersci.com/shop/products/pacific-hemostasis-sicklescreen-assay-kit/p-4529248

01:10:16 Joyal Meyer: @brielle - yes! ND it's manageable for us, but not for states like yours!! :(

01:10:20 Kimberly Noble Piper: Beth A. Tarini, Margaret Alison Brooks, and David G. Bundy. "A Policy Impact Analysis of the Mandatory NCAA Sickle Cell Trait Screening Program." Health Services Research. 2012 Feb;47(1 Pt 2):446-61. Online version accessed 8/4/2022 at https://pubmed.ncbi.nlm.nih.gov/22150647/

01:10:45 Michelle Mills: @Suzanne Yes, agreed.

01:11:09 Annie Ross - Womack: The SCDAA is in contact with the NCAA Medical Advisory Committee regarding this issue. There have been several calls.

01:11:11 Joyal Meyer: Great comment @suzanne

01:11:12 Kisha Hampton- IHTC: The rule change was approved in April this year. As soon as the rule came out, the coaches and athletes were put on notice, they were informed of the rule change in April, May, June, and July. The problem was that the athletes, and coaches to a lesser extent, did not really pay attention to the changes until the last minute. Because in the past they were permitted to sign a waver to sickle cell testing. Next year, this will not be a problem. Only the new students will be required to show proof of the test, which will decrease the amount of tests needed by a substantial amount. From about 450 at Anderson to about 100 total from here on out each year.

01:12:13 Kisha Hampton-IHTC: Yes there are team meetings, letters home, conference meetings, etc. In all of these meetings, this was mentioned, but I don't think anyone really understood the time delay with getting the results. We looked at setting up testing on campus, but the health department here does not do them, and, honestly, with three months of notice, the athletes very easily could purchase their own tests, or see their family doctor for the tests and many did.

Perhaps, what could be done is a letter or something like that to the high schools in the state mentioning that the athletes who will be participating in the NCAA next year will need to have their sickle cell tests recorded. The IHSAA does have a yearly meeting with the high school ADs and that information could be brought to their attention at that time, and that may be a good start. Or, honestly, if it were put into the high school physical form, that also may be a good idea, if we were to look at it from a prevention perspective. Could we design a database for

01:12:40 Kisha Hampton- IHTC: Perhaps, what could be done is a letter or something like that to the high schools in the state mentioning that the athletes who will be participating in the NCAA next year will need to have their sickle cell tests recorded. The IHSAA does have a yearly meeting with the high school ADs and that information could be brought to their attention at that time, and that may be a good start. Or, honestly, if it were put into the high school physical form, that also may be a good idea, if we were to look at it from a prevention perspective. Could we design a database for all Indiana high school students where they upload their sickle cell documents and it can be accessed?

01:13:06 Brielle Easton: Also we had 50+ calls a day in NJ from parents calling that "their kid was not allowed on the field" and wanted it faxed within 30 min....I don't think the parents even understand that this is not what we primarily do

01:13:12 Kisha Hampton- IHTC: Sorry I had to paste it in pieces. This is a message from the Anderson University athletic director.

01:13:15 Brielle Easton: The week that summer athletes started

01:13:17 Krystal Baumert: I recall what Debra is saying as well from 2010. My daughter was a Division 1 recruit in 2010 and most of the athletes at that time were signing waivers, the college told us.

01:13:34 Shawn Moloney: Does anyone who just releases the hemoglobinopathy results put a caveat that these are just screening and not diagnostic?

01:13:43 Kshea Hale: Thank you for all of the great comments! After the webinar, please complete the following survey <u>https://www.surveymonkey.com/r/RXCW8FP</u>. Your participation is greatly appreciated.

01:13:59 Joyal Meyer: I would think that parents have no idea how complex these requests are and how it is a complicated process. They just want the results.

01:15:00 Joyal Meyer: It would be helpful to have a part 2 discussion to this in another month to see where we are with things if possible?

01:15:00 suzanne canuso: Thank you for hosting this very rich discussion on a timely and important topic.

01:15:29 Joyal Meyer: So that we don't lose momentum and have these same discussions next year before college starts. :)

01:15:45 Sydney Williamson-White: Agree Joyal - follow up webinar would be great

01:15:51 Jillian Chance: Perhaps, states need to set policies that are protective of the work that they do that set boundaries about the timeliness these results will be released. If we are not the fastest, easiest route, perhaps we can get the NCAA's attention when we are not cooperating as well.

01:16:07 Jenn Weaver - IN Dept of Health: Thank you for arranging this opportunity for conversation. It is encouraging to hear similar challenges in different states. We will get there!

01:16:07	Diane Recker: Agree, follow up webinar please
01:16:08 state?	Kristi Murphy: should NCAA be made aware of different retention policies for each
01:16:15	Jodi Philippon: Thank you!!!
01:16:23	Marie Burlette: Thank you!!!
01:16:23	Sarah Bradley: Thank you for this great discussion
01:16:28	Fran Altmaier: Thank you!!
01:16:30	Joyal Meyer: Thank you so much for getting us all together!!
01:16:30	Lorrie Folmar: Thank you!
01:16:30	Sydney Williamson-White: Thank you
01:16:31	Emily Eisenstein: Thank you so much! Really great discussion!
01:16:33	LaPortia Barrows: Thank you
01:16:33	TaLana Hughes: This is a very much needed conversation thank you!!
01:16:35	Mary Lowe: Thank you!!
01:16:35	Joyal Meyer: WE appreciate you!

- 01:16:36 Tracey Bishop: Thanks everyone!
- 01:16:36 Kimberly Noble Piper: Thanks!